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# Cognitive and Emotional Barriers to Colorectal Cancer Surveillance: Increasing Screening Rates within the Community

by

Cari N. Krzyzaniak

Thesis

Submitted to the College of Health and Human Services

Eastern Michigan University

in partial fulfillment of the requirements

for the degree of

MASTER OF SCIENCE

in

Clinical Research Administration

Thesis Committee:

Stephen A. Sonstein, PhD, Chair

July 15, 2008

Ypsilanti, Michigan

# Dedication

I would like to dedicate this thesis to my family. I am tremendously grateful for their love and support throughout the course of my graduate studies.

# Acknowledgments

I would like to acknowledge my colleagues at the University of Michigan Comprehensive Cancer Center Clinical Trials Office (CTO). Their passion for research changes cancer therapy. My work in the CTO served as inspiration for this thesis.

I would also like to recognize the faculty at Eastern Michigan University who volunteered to participate in this study. This research project would not have been possible without the efforts of the study participants.

Finally, I would like to extend my gratitude to my thesis advisor, Dr. Stephen Sonstein, for his patience and guidance during this project.

#### Abstract

Background: The rate of colorectal cancer (CRC) screening in the United States continues to be low, allowing colorectal cancers to remain undiagnosed and mortality rates to remain high. Current literature points to lack of education, healthcare access, and physician counseling as key barriers to screening, in addition to cognitive-emotional apprehensions.

Objectives: This study examined whether cognitive-emotional apprehensions are barriers to screening despite physician recommendation. Moreover, it examined what particular cognitive-emotional barriers inhibit participation and how these barriers can potentially be alleviated.

Methods: A convenience sample of 40 faculty members at Eastern Michigan University were surveyed about attitudes toward screening.

Results: One half of non-screeners reported that cognitive-emotional apprehensions limited their participation in screening tests. Predictors of adherence included concerns about embarrassment or modesty, concerns about test preparation, fear of pain, and fear of finding cancer.

Conclusions: Cognitive-emotional apprehensions are significant barriers to CRC screening and may be improved by patient counseling.

# Table of Contents

Dedication	ii
Acknowledgments	iii
Abstract	iv
List of Tables.	vii
Chapter I: Introduction	1
Colorectal Cancer Screening.	1
Statement of the Problem	3
Purpose of the Study	3
Research Questions	3
Chapter II: Literature Review	5
Patient Education	5
Access to Healthcare	6
Physician Counseling	7
Cognitive and Emotional Barriers	7
Chapter III: Research Methodology	9
Sample Selection	9
Human Subjects Protection	9
Data Collection	10
Chapter IV: Presentation and Analysis of Data	11
Demographic Data	11
Research Question #1	13
Research Question #2	13

Research Question #3	14
Chapter V: Discussion	18
Chapter VI: Conclusions	20
Implications for Clinical Practice and Public Campaign	20
Limitations of the Study	20
Recommendations for Further Research	21
References	22
Appendices	25
Appendix A: College of Health and Human Services Human Subject Review	
Committee Approval Letter	26
Appendix B: Implied Informed Consent Form	27
Appendix C: Survey	28

# List of Tables

<u>Table</u>		<u>Page</u>
1	Demographic Characteristics of Study Sample (N = 40)	12
2	Barriers to Colorectal Cancer Screening Reported by Non-Screeners	16
3	Colorectal Cancer Screening Attitudes Reported by Study Participants	17

#### Chapter I: Introduction

Colorectal cancer (CRC) is a disease characterized by the uncontrolled growth and proliferation of cells that form in the tissues of the colon and rectum, two segments of the large intestine. It is the third most common form of cancer in the United States and the second leading cause of cancer-related deaths. The National Cancer Institute (2008) estimates that there will be 148,810 new cases and 49,960 deaths from colon and rectal cancer in the United States in 2008. Thus, colorectal cancer is an especially prominent and fatal disease in the country.

Although the causes of colorectal cancer are multifaceted, there are common clinical features of the disease. The risk of developing colorectal cancer increases with age; the peak incidence occurs in adults between 50 and 60 years old (Price & Wilson, 2003). The most common symptoms include a change in bowel habits, rectal bleeding or blood in the stool, diarrhea or constipation, abdominal pain and distention, fatigue, anemia, and weight loss. In some cases, however, colorectal cancer may present without symptoms in people with no known history or predisposing factors; as a result, regular surveillance is critical for the early detection of the disease.

# Colorectal Cancer Screening

Colorectal cancer is highly detectable through regular screening programs.

Screening allows healthcare professionals to detect and remove precancerous polyps before invasive cancer develops or to diagnose cancer early when treatment is most effective. The Harvard Center for Cancer Prevention (1999) reports that regular screening, combined with a healthy lifestyle, can prevent more than half of all colon cancers in the United States. Moreover, according to the Centers for Disease Control and

Prevention (2007), the five-year relative survival rate is 90% when physicians diagnose colorectal cancer at the early stages. Screening is therefore an important mechanism for colorectal cancer prevention, detection, and survival.

There are several procedures for colorectal cancer surveillance, including the fecal occult blood test (FOBT), double-contrast barium enema (DCBE), flexible sigmoidoscopy, and colonoscopy. The FOBT checks for the presence of microscopic amounts of blood in the stool, a potential symptom of colorectal cancer, by placing a small sample of stool on a chemically treated card. In contrast, the DCBE test uses an enema containing a barium dye and a series of x-rays to look for abnormalities in the inner contours of the colon and rectum. The sigmoidoscopy and colonoscopy allow physicians to examine the inside of the rectum or colon with a fiber-optic scope to look for abnormal areas or growths; physicians may then remove samples of any abnormal tissues for microscopic evaluation and diagnosis. Regardless of the test, the procedures aim to detect precancerous polyps or localized carcinomas.

Although physicians are not in consensus on which screening tests should be used or how often adults at average risk for cancer should be tested, all professional guidelines emphasize the importance of regular surveillance. Price & Wilson (2003) note that, for asymptomatic persons, men and women over 50 years of age should have a FOBT annually and a sigmoidoscopy examination every three to five years. Similarly, the American Cancer Society (2007) recommends that those people at average risk for cancer and without any specific symptoms have a FOBT yearly, a flexible sigmoidoscopy or DCBE every five years, or a colonoscopy every ten years, beginning at age 50. Persons with a personal or family history of colorectal cancer should consider beginning

screening earlier and/or undergoing screening procedures more frequently than the guidelines recommend.

#### Statement of the Problem

Despite these guidelines, colorectal cancer screening rates continue to be low in the United States. According to the Centers for Disease Control and Prevention (2006), its 2000 National Health Interview Survey reveals that only 42.5% of adults age 50 or older had a sigmoidoscopy or colonoscopy within the previous ten years or had a FOBT within the preceding year. As a direct result, physicians detect less than 40% of colorectal cancers early, which means that as many as 60% of colorectal cancer deaths could be prevented if screening rates increased (Centers for Disease Control and Prevention, 2006). It is therefore important to understand the factors contributing to low screening adherence to prevent mortality from colorectal cancer in the future.

## *Purpose of the Study*

This research study explored the cognitive and emotional apprehensions that discourage participation in colorectal cancer screening tests despite patient education, availability of health insurance, and physician recommendation.

# Research Questions

This study addressed the following research questions:

- 1. Are cognitive and emotional apprehensions significant barriers to colorectal cancer screening?
- 2. What are the particular cognitive and emotional barriers that inhibit participation in colorectal cancer screening tests?

3.	How can cognitive and emotional barriers to colorectal cancer screening be			
	alleviated?			

## Chapter II: Literature Review

Current literature points to colorectal cancer screening barriers related to patient education, access to healthcare, physician counseling, and cognitive-emotional apprehensions.

#### Patient Education

Knowledge of colorectal cancer is one of the key predictors of patient screening. Studies indicate that never-screened patients have poor knowledge of cancer warning signs, symptoms, and risk factors and less understanding of colorectal cancer incidence and treatment outcomes (Harewood, Wiersema, & Melton, 2003; Shokar, Vernon, & Weller, 2005). For example, Harewood et al. (2003) report that never-screened patients significantly underestimate the risk to an average 60-year-old person developing colon cancer and are more likely to underestimate the success of treatment for early stage colon cancer when compared to estimates from previously screened patients. Thus, patients with poor knowledge of colorectal cancer are less likely to participate in screening procedures.

A lack of screening awareness can also hinder patient participation in colorectal cancer surveillance. Patients who do not understand the concept of screening, who lack knowledge of screening tests, or who lack awareness of the need for screening are less likely to adhere to surveillance guidelines (Wee, McCarthy, & Phillips, 2004; Shokar et al., 2005; Klabunde, Schenck, & Davis, 2006). Shoker et al. (2005) report that a significant number of study participants "did not comprehend the purpose of screening for cancer, were not able to distinguish screening tests from any other kind of test, and did not realize that screening is preformed when a person feels well" (p. 345). Similarly,

Wee et al. (2005) specify that the majority of respondents who failed to participate in screening tests report their primary reason as being unaware of the need for screening. Thus, screening awareness greatly influences colorectal cancer surveillance rates.

Access to Healthcare

Access to healthcare coverage is an additional predictor of colorectal cancer surveillance. Studies show that lack of health insurance and financial resources are significant barriers to screening in the United States (Denberg, Melhado, Coombes, Beaty, Berman, Byers, Marcus, Steiner, & Ahnen, 2005; Kabunde, Vernon, Nadel, Breen, Seeff, & Brown, 2005; Tabbarah, Nowalk, Raymund, Jewell, & Zimmerman, 2005). Denberg et al. (2005) report that particular health plans predict low adherence to screening and that patients cite cost as a common logistical obstacle. Similarly, Tabbarah et al. (2005) note that 19% of African American participants in their study choose not to participate in screening tests because of cost. Financial limitations, therefore, restrict patient access to screening tests and discourage adherence to colorectal cancer screening guidelines.

Similar to patients who lack healthcare coverage, screening also tends to be low among patients who lack a usual source of healthcare. Patients never screened for colorectal cancer are less likely to have a regular primary physician (Harewood et al., 2002). Moreover, patients who visit their physicians infrequently are less likely to report colorectal cancer screening than patients who visit their physicians more frequently (Tabbarah et al., 2005). Thus, patients who receive infrequent medical attention are less likely to participate in colorectal cancer screening tests. A lack of regular healthcare, then, discourages compliance with screening.

## Physician Counseling

Physician counseling is one of the prime determinants of colorectal cancer screening. Patients are not likely to participate in colorectal cancer screening tests without a recommendation from their physician (Klabunde et al., 2005; Wee et al., 2005; Harewood et al., 2005; Wang, Liang, Chen, Cullen, Feng, Yi, Schwartz, & Mandelblatt, 2006; Klabunde et al., 2006; Teng, Friedman, & Green, 2006). Klabunde et al. (2005) report that patients who visited a doctor in the past year or had health insurance were more likely to report lack of physician recommendation as the main reason for not participating in screening tests. Similarly, Wang and colleagues (2006) report that women receiving recommendations for colon cancer screening have more than three-fold increased odds of participating in screening tests than those who do not receive recommendations. Thus, inadequate physician counseling has a significant impact on colorectal cancer screening rates; without physician recommendations, patients are not likely to pursue screening tests.

Patient perception of physician support may also be associated with colorectal cancer screening rates. Patients are more likely to participate in colon cancer screening if they believe their physicians support the tests. In 2005, Tabbarah and colleagues found that patients who believed their doctor thought that they should be tested for colon cancer were 19 times more likely to report a colonoscopy than patients without the belief. Thus, perceptions of physician support appear to influence screening rates.

#### Cognitive and Emotional Barriers

In addition to perceptions of physician support, current literature suggests that other cognitive and emotional apprehensions may act as barriers to colorectal cancer

screening. Studies show that patients commonly express fear of pain or discomfort, fear of the test preparation, and concerns about modesty or embarrassment as reasons for avoiding participation in screening tests (Harewood et al., 2002; Walsh, Kaplan, Nguyen, Gildengorin, McPhee, & Perez-Stable, 2004; Denberg et al., 2005). Similarly, Greiner, Born, Nollen, & Ahluwalia (2005) report that fear is one of the most commonly stated barriers to screening with fatalism and mistrust. Cognitive and emotional factors, then, are likely to be significant barriers to colorectal cancer screening in spite of patient education, healthcare access, and physician recommendation.

#### Chapter III: Research Methodology

Sample Selection

The target population for this study consisted of adults at average or greater than average risk for developing colorectal cancer who have received physician counseling regarding colorectal cancer screening tests. As a result, participants were required to (1) be 50 years of age or older, (2) have any type of healthcare coverage, and (3) have had a physician recommend that they be screened for colorectal cancer in the past. Participants under the age of 50 years who did not have healthcare coverage or who had not received a physician recommendation to undergo colorectal cancer surveillance were excluded from the study.

Human Subjects Protection

Prior to initiating this research, the Investigator submitted a Request for Approval of Research Involving Human Subjects to the Eastern Michigan University College of Health and Human Services Human Subjects Review Committee (HSRC) for review and approval. The HSRC approved the study for initiation on February 12, 2008. Refer to Appendix A for a copy of the HSRC Approval Letter.

All potential study participants were informed of the study purpose and procedures by means of informed consent. The informed consent form indicated that participation in this study was voluntary. All potential participants had the right to refuse participation or withdraw from the study prior to mailing in the survey. They also had the right to omit any survey question. As the form indicated, by completing and returning the surveys, participants were providing their consent to join the study. Please refer to Appendix B for the Implied Informed Consent Form.

9

In addition, all data collected for this study were anonymous and confidential.

Participants were instructed via the implied informed consent form and the survey directions not to sign their names to any of the forms or study questionnaires. There was no record linking the subjects and the research.

#### Data Collection

Subsequent to HSRC approval, the Investigator distributed study information to Eastern Michigan University (EMU) faculty via mail. Approximately 150 unselected adults received the study packet and were asked to consider participating in the research study. The study packet included the informed consent form, colorectal cancer screening survey, and a self-addressed stamped envelope. Upon completion of the survey, the informed consent form instructed participants to return the research information to the Investigator via postal mail in the provided envelope. Refer to Appendix C for the Colorectal Cancer Screening Survey used in this study.

#### Chapter IV: Presentation and Analysis of Data

# Demographic Data

The Investigator delivered 150 surveys to potential participants for this study. Forty-seven participants returned surveys to the study team, which equates to a 31.3% response rate. Seven participants did not meet the eligibility criteria; as a result, their data were excluded from analysis. Thus, a final sample of 40 EMU faculty members participated in this study.

Among the eligible participants, 24 adults reported prior participation in colorectal cancer screening tests. The majority of these participants were 50 to 59 years old (66.7%) with the other participants being 60 to 69 years old (33.3%). Twenty participants were female (83.3%) and 4 participants were male (16.7%). In terms of ethnicity, 22 of the participants were Caucasian (91.7%) and 2 of the participants were African American (8.3%).

There were 16 adults, the *non-screeners*, who reported that they had not been screened for colon or rectal cancer in the past. Fourteen of these participants were 50 to 59 years old (87.5%) and 2 participants were 60 to 69 years old (12.5%). Twelve participants were female (75%) and 4 participants were male (25%). In terms of ethnicity, all 16 participants were Caucasian. See Table 1 for detailed demographic data of the study sample.

Table 1  $Demographic\ Characteristics\ of\ Study\ Sample\ (N=40)$ 

Variable	Non-Scr	eeners (n =16)	Screeners (n =24)		
Gender					
Male (20.0%)	4	(25.0%)	4	(16.7%)	
Female (80.0%)	12	(75.0%)	20	(83.3%)	
Age category (y)					
50 to 59 (75.0%)	14	(87.5%)	16	(66.7%)	
60 to 69 (25.0%)	2	(12.5%)	8	(33.3%)	
70+ (0.0%)	0	(0.0%)	0	(0.0%)	
Race					
African American (5.0%)	0	(0.0%)	2	(8.3%)	
Asian (0.0%)	0	(0.0%)	0	(0.0%)	
Caucasian (95.0%)	16	(100.0%)	22	(91.7%)	
Education Level					
Some college (0.0%)	0	(0.0%)	0	(0.0%)	
College graduate (20.0%)	8	(50.0%)	0	(0.0%)	
Graduate school (80.0%)	8	(50.0%)	24	(100.0%)	
Heath Status					
Excellent (60.0%)	8	(50.0%)	16	(66.7%)	
Good (37.5%)	7	(43.7%)	8	(33.3%)	
Fair (2.5%)	1	(6.3%)	0	(0.0%)	
Poor (0.0%)	0	(0.0%)	0	(0.0%)	

#### Research Question #1

The first objective of this research was to evaluate whether cognitive and emotional opinions were significant barriers to colorectal cancer surveillance. Among the non-screeners, the most common barriers to screening reported were cognitive-emotional apprehensions and logistical obstacles. Specifically, 50% of non-screeners named personal feelings as the primary reason for not participating in colorectal cancer screening tests. Logistical issues were named as the primary reason by 37.5% of non-screeners, citing cost, time away from work, and transportation problems as specific reasons for noncompliance (Table 2). As the primary reason for noncompliance, no participants reported lack of knowledge about screening or feelings that screening tests are unnecessary.

#### Research Question #2

The second objective of this research was to explore the specific cognitive and emotional barriers that inhibit participation in colorectal cancer screening tests.

According to the results, non-screeners commonly expressed embarrassment, fear of discomfort, concerns regarding the test preparation, and fear of finding cancer as cognitive-emotional reasons for screening noncompliance. Non-screeners did not report fatalism or feelings of mistrust. In addition, non-screeners did not report a lack of physician support toward screening.

Participants commonly reported concerns about embarrassment or modesty as cognitive-emotional barriers to colorectal cancer surveillance. As an explanation for noncompliance, 50% of non-screeners reported that colorectal cancer screening tests are embarrassing (Table 2). Furthermore, 62.5% of non-screeners reported that they would

be more willing to be screened for colon cancer if they were less modest, compared to 8.3% of screeners (Table 3). All participants who reported concerns about modesty or embarrassment were female.

In addition to apprehensions about embarrassment and modesty, participants commonly reported themes of fear as barriers to colorectal cancer screening. Seventy-five percent of non-screeners reported fear of discomfort or concerns regarding the test preparation as reasons for noncompliance with screening guidelines. Moreover, 25% of non-screeners expressed that fear of finding cancer limited their participation in screening tests (Table 2). Both male and female participants reported fear as a common barrier.

Participants in this study did not report fatalistic beliefs, feelings of mistrust, or lack of physician support as barriers to colorectal cancer surveillance. No participants felt that cancer is inevitable, and all non-screeners agreed that if colon cancer was detected early by tests, it could likely be cured. All participants agreed to some extent that they trusted screening tests to be thorough and accurate, and approximately 88% of non-screeners and 92% of screeners agreed that their physician supports their participation in colorectal cancer screening tests (Table 3).

#### Research Question #3

The third objective of this research was to explore how physicians or public campaigns could potentially alleviate cognitive and emotional apprehensions to colorectal cancer screening. According to the results, 62.5% of non-screeners reported that they would be more willing to be screened for colorectal cancer if they were able to choose the gender of the physician performing the test; only 8.3% of screeners shared this opinion (Table 3). In addition, one-half of non-screeners reported that they would be

more willing to undergo a colonoscopy if they could be sedated during the test, and all non-screeners reported that they would be more willing to participate in screening tests if the examination consisted of a blood test only.

Table 2

Barriers to Colorectal Cancer Screening Reported by Non-Screeners

Barrier	Total (n =16)	
CRC Knowledge		
Not at risk for CRC	4	(25.0%)
No symptoms	4	(25.0%)
Cognitive-emotional barriers		
Fatalism	0	(0.0%)
Embarrassment	8	(50.0%)
Fear of test preparation	6	(37.5%)
Fear of pain or discomfort	6	(37.5%)
Fear of finding cancer	4	(25.0%)
Logistical obstacles		
Busy	0	(0.0%)
Time away from work	8	(50.0%)
Transportation problems	4	(25.0%)
Cost	4	(25.0%)

Table 3

Colorectal Cancer Screening Attitudes Reported by Study Participants

Attitude	Non-Screeners (n =16) (%)	Screeners (n =24) (%)	Total (n =40) (%)
Trust that CRC screening tests are thorough and accurate	100.0	100.0	100.0
Believe their physician supports CRC screening	87.5	91.7	90.0
Believe if CRC was detected early by tests, it could be cured	100.0	91.7	95.0
More likely to participate if able to choose the gender of the physician	62.5	8.3	30.0
More likely to participate in colonoscopy if sedated	50.0	83.3	70.0
More likely to participate in a blood test	100.0	41.7	65.0
More likely to participate if less modest	62.5	8.3	30.0

#### Chapter V: Discussion

Based on the survey results, the investigator identified several cognitive and emotional apprehensions that discourage participation in colorectal cancer surveillance, including patient concerns about embarrassment and modesty, concerns about the unpleasantness of the test preparation, fear of discomfort associated with the screening procedures, and fear of finding cancer. These apprehensions existed despite education, the availability of health insurance, and physician recommendations for screening.

Non-screeners reported concerns about embarrassment and modesty as the most common cognitive-emotional barriers to colorectal cancer surveillance. Although the sample did not include a large number of men, it is interesting to note that all participants who reported these concerns were female. Cultural perceptions of body image may promote these types of feelings in women and discourage adherence to screening tests. The results show that allowing patients to choose the gender of the physician performing the test may help decrease these apprehensions and increase initial screening rates. Since most screeners did not report a gender preference or feelings of modesty, concerns about embarrassment should significantly decrease after participation.

In addition to concerns about embarrassment and modesty, non-screeners also reported themes of fear as barriers to screening, including fear of pain or discomfort associated with colonoscopy. Since non-screeners reported that they would be more willing to participate in screening tests if they could be sedated or if the examination consisted of only a blood test, it appears that fears may relate to the invasive nature of the test. Thus, it is evident that these apprehensions deserve greater attention in patient

counseling and education efforts. Physicians may also wish to promote the alternatives to colonoscopy for these select patients.

One-fourth of non-screeners also reported fear of finding cancer as a barrier to screening. Even though all participants agreed that getting a colon cancer test is a wise thing to do, a cancer diagnosis could expose patients to a variety of emotions and burdens that some people may not be prepared to manage. It would be interesting for future studies to research this specific apprehension further to isolate the particular fears of diagnosis (e.g. concerns about recovery, cost of treatment, and/or time involved with treatment).

In contrast to earlier studies, fatalistic beliefs, feelings of mistrust, and perceptions of physician support were not predictors of screening adherence. This may be due to the small sample size or the lack of representation of different minority or socioeconomic populations. These concerns may also not be relevant to this sample of participants, as the majority were highly educated professionals. It is interesting to note, however, that nearly all participants agreed that their physician supports participation in colorectal cancer screening tests. Thus, rather than physician counseling, the non-screeners within this community may need an additional type of intervention to promote screening adherence.

#### Chapter VI: Conclusions

Implications for Clinical Practice and Public Campaign

This study showed that cognitive and emotional apprehensions are significant barriers to colorectal cancer surveillance. Cognitive-emotional predictors of adherence included concerns about embarrassment and modesty, concerns about the unpleasantness of test preparation, fear of pain or discomfort associated with the screening procedures, and fear of finding cancer. It is therefore imperative that future interventions focus on means to overcome these cognitive-emotional barriers and increase screening rates.

Future interventions to overcome cognitive-emotional apprehensions may allow clinics to cater to patient preferences or include public campaigns that promote additional education. Patient concerns regarding embarrassment or modesty may be alleviated by allowing patients to choose the gender of the physician performing the screening tests. Physician counseling and patient education efforts may also help decrease concerns about colonoscopy or the test preparation. Ultimately, a comprehensive approach should be developed to address the multiple barriers that influence participation in colorectal cancer screening tests.

*Limitations of the Study* 

The investigator carried out this study within a single academic institution using a convenience sample of faculty members. The sample size used in this study was relatively small, and male and minority populations were not well represented.

Nonetheless, the investigator suspects the themes of embarrassment and fear observed in this study to be applicable to other populations in other areas of the country.

20

## Recommendations for Further Research

To confirm the results of this study, future investigators should replicate this research in a larger patient population using a random sample of study participants. The investigators should ensure that male participants and minority populations are included in future studies since they were not well represented in this research. It may also be interesting for future studies to highlight distinct cultures and examine if cognitive-emotional apprehensions influence colorectal cancer screening rates in the populations differently.

Since women in this study were more likely to report concerns about embarrassment and modesty, future studies may wish to focus on the cognitive-emotional apprehensions that differ between genders. There may be other important cognitive-emotional barriers to colorectal cancer screening that affect men and women differently. Future interventions can then tailor messages to different members of the community.

This research did not collect demographic data relating to participant marital status. It would be interesting for future studies to examine how martial status influences colorectal cancer screening rates in the general population. It would also be interesting to examine how a patient's perception of support for screening by a spouse or significant other compares to perceptions of support by a physician. Personal relationships may serve as an additional barrier to colorectal cancer screening.

21

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Appendices

# Appendix A: College of Health and Human Services Human Subject Review Committee

## Approval Letter



#### EASTERN MICHIGAN UNIVERSITY

February 12, 2008

Cari Krzyzaniak c/o Stephen Sonstein, PhD School of Health Sciences Eastern Michigan University Ypsilanti, MT 48197

Dear Ms. Krzyzaniak ,

The CHHS Human Subject Review Committee has reviewed your request entitled "Barriers to Colorectal Cancer Surveillance: Increasing Screening Rates within the Community" and it is approved for initiation.

The Committee may request further approval if secondary analysis of the data is conducted.

Sincerely,

Stephen A. Sonstein, PhD

Chair, CHHS Human Subjects Review Committee

#### Appendix B: Implied Informed Consent Form

#### Implied Informed Consent to Participate in a Research Study

Study Title: Cognitive and Emotional Barriers to Colorectal Cancer Surveillance: Increasing Screening Rates within the Community.

Investigator: Cari Krzyzaniak, BA

#### Purpose

You have been selected to participate in a research study in partial fulfillment of the requirements for a Master of Science degree in Clinical Research Administration at Eastern Michigan University. This research will focus on the barriers to colorectal cancer screening. The goal of this project is to identify the cognitive and emotional barriers that limit participation in colorectal cancer screening tests in our community. This information can then be utilized so that future public campaigns can adequately tailor messages to the community and potentially increase rates of colorectal cancer screening.

#### Procedures

If you agree to participate, you will be asked to fill out a short survey. The survey should take about 5-10 minutes to complete. The questions in the survey pertain to your demographic information and medical history, knowledge of colorectal cancer, and attitudes concerning colorectal cancer screening tests. After you complete the survey, you will put it into the preaddressed envelope with postage provided, seal it, and mail it to the study team.

#### Risks

The study procedures involve no foreseeable risks or harm to you. Some of the questions in the survey about your experience and feelings of colorectal cancer may make you uncomfortable. You can choose, at any time, not to answer a question. You may also withdraw from the study prior to mailing in the forms.

#### Benefits and Compensation

There is no direct benefit to you for participating in this research study. You will receive no compensation for participation.

#### Confidentially

Please DO NOT sign your name to any of the forms, as all responses will be kept confidential. Surveys will be kept in a locked file cabinet and shredded upon completion of the study. Only the study team will have access to the anonymous data. The data will be handled confidentially at all times. The results of the study will be made available in a paper presented to Eastern Michigan University and possibly published in a professional journal. If you wish to receive a copy of the research results, please contact the faculty advisor, Stephen Sonstein, PhD, at (734) 487-1238.

#### Voluntary Participation

Your participation is voluntary. You are under no obligation to participate. You may refuse to participate at any time during the study without penalty. If you decline to participate, you may destroy the blank survey. However, once you mail in the survey, you cannot request to withdraw from the study since your specific form cannot be identified. If you have any questions or concerns about the study, please contact Dr. Stephen Sonstein, College of Health and Human Services Human Subjects Review Committee Chair, at (734) 487-1238.

#### Implied Informed Consent

By completing and returning this survey, you verify that:

- You have understood the purpose of this study
- You have voluntarily agreed to participate
- You are at least 18 years of age

Please return your completed questionnaires in the attached envelope. Thank you for your time and consideration in participating in this research study.

#### Appendix C: Survey

#### COLORECTAL CANCER SCREENING SURVEY

SHOULD YOU CHOOSE TO PARTICIPATE IN THIS RESEARCH STUDY, PLEASE ANSWER THE FOLLOWING QUESTIONS TO THE BEST OF YOUR ABILITY. PLEASE <u>DO NOT</u> SIGN YOUR NAME TO ANY OF THE FORMS. YOUR ANSWERS WILL BE CONFIDENTIAL.

- 1. GENDER:
  - Male
  - Female
- AGE:
  - Younger than 40
  - o 40-49
  - o 50-59
  - o 60-69
  - o 70 or older
- 3. RACE:
  - African American/black
  - Asian
  - Caucasian/white
  - Hispanic
  - Native American
  - Other: \_\_\_\_\_\_
- 4. HIGHEST LEVEL OF EDUCATION:
  - High school or less
  - Some college
  - College graduate
  - Graduate/professional school
- 5. DO YOU HAVE ANY KIND OF HEALTH CARE COVERAGE?
  - Yes
  - o No
- 6. WHAT IS YOUR CURRENT HEALTH STATUS?
  - Excellent
  - Good
  - Fair
  - Poor
- DO YOU KNOW SOMEONE WITH COLON OR RECTAL CANCER?
  - o Yes
  - o No
- 8. HAVE YOU EVER LOOKED FOR INFORMATION ON COLON CANCER?
  - o Yes
  - o No
- DO YOU BELIEVE GETTING A COLON CANCER TEST IS A WISE THING TO DO?
  - Yes
  - o No
  - Undecided

- 10. HAS A DOCTOR RECOMMENDED THAT YOU BE SCREENED FOR COLON CANCER?
  - Yes
  - o No
- 11. HAVE YOU BEEN SCREENED FOR COLON OR RECTAL CANCER IN THE PAST?
  - o Yes
  - o No
  - Not sure
- 12. PLEASE SELECT THE SCREENING TEST(S) YOU HAVE HAD FOR COLON OR RECTAL CANCER. PLEASE SELECT ALL ANSWERS THAT APPLY TO YOU.
  - Fecal occult blood test (FOBT)
  - Barium Enema (DCBE)
  - Sigmoidoscopy or colonoscopy
  - Not sure
  - o I have not been tested
- 13. IF YOU HAVE NOT BEEN SCREENED FOR COLON CANCER, WHAT IS YOUR PRIMARY REASON FOR NOT HAVING A TEST?
  - o I did not know about screening
  - The tests are unnecessary
  - Logistical issues (time, scheduling challenges, cost, etc.)
  - Personal feelings (fear, anxiety, embarrassment, etc.)
  - Not applicable
- 14. IF YOU HAVE <u>NOT</u> BEEN SCREENED FOR COLON CANCER, PLEASE SELECT YOUR REASON(S) FOR NOT HAVING THE TEST. PLEASE SELECT ALL ANSWERS THAT APPLY TO YOU.
  - I am not at risk for colon cancer
  - o I do not have any symptoms
  - o Cancer is unavoidable
  - I am too busy
  - o I would have to miss work
  - o I need someone to drive me
  - o The test is too expensive
  - I do not want to find out that I have cancer
  - The test preparation is disagreeable
  - o The tests may be uncomfortable
  - o The tests are embarrassing
  - Not applicable/none of the above

QUESTIONS 15-22: FOR THE FOLLOWING STATEMENTS, PLEASE INDICATE THE EXTENT TO WHICH YOU AGREE OR DISAGREE:

		Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
15.	I TRUST THAT THE SCREENING TESTS FOR COLON CANCER ARE THOROUGH AND ACCURATE.	0	0	0	0	0
16.	MY DOCTOR THINKS I SHOULD BE CHECKED FOR COLON CANCER.	0	0	0	О	0
17.	I FREQUENTLY WORRY ABOUT GETTING COLON CANCER.	0	0	0	О	0
18.	I PLAN TO BE SCREENED FOR COLON CANCER IN THE FUTURE.	0	0	0	О	0
19.	IF COLON CANCER WAS DETECTED EARLY BY TESTS, IT IS LIKELY THAT IT COULD BE CURED.	0	0	0	o	0
20.	I AM CONCERNED THAT THE DETECTION OF CANCER WOULD CAUSE ME FINANCIAL PROBLEMS.	0	0	0	0	o
21.	I AM CONCERNED THAT THE DETECTION OF CANCER WOULD CAUSE MY FAMILY DISTRESS.	0	0	0	0	0
22.	MY LIFE IS TOO DEMANDING TO HAVE CANCER RIGHT NOW.	0	0	0	o	0

QUESTIONS 23-27: PLEASE INDICATE THE EXTENT TO WHICH YOU AGREE OR DISAGREE TO THE FOLLOWING: I WOULD BE MORE WILLING TO BE SCREENED FOR COLON CANCER IF...

		Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
23.	I WAS ABLE TO CHOOSE THE GENDER OF THE DOCTOR PERFORMING THE TEST.	0	0	0	0	0
24.	I WAS ABLE TO BE SEDATED DURING A COLONOSCOPY.	0	0	0	0	0
25.	THE TEST WAS ONLY A BLOOD TEST.	0	0	0	0	0
26.	I WAS LESS MODEST.	0	0	0	0	0
27.	I KNEW THE RESULTS WOULD SHOW THAT I DID NOT HAVE CANCER.	0	0	0	0	0