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# A Colorectal Cancer Screening Project in an Old Order Mennonite Community: Capstone Project Technical Report

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A Colorectal Cancer Screening Project in an Old Order Mennonite Community

Capstone Project Technical Report

Presented to:

The College of Nursing

University of Kentucky

by

Maria Eve Main

Project Advisor: Dr. Marcia Stanhope RN, DSN, FAAN

Spring 2010

# COLORECTAL CANCER SCREENING

## Acknowledgements

I would like to thank Dr. Marcia Stanhope, the chair of my committee, for her guidance, patience, and encouragement. I would also like to acknowledge Dr. Susan Jones for facilitating my work and without whom this project would not have been possible. I would also like to acknowledge Dr. Margaret Hickman for her guidance. Lastly, I would like to acknowledge my clinical mentor Dr. Melissa Thomas whose expertise and guidance has been invaluable.

I would also like to acknowledge that partial funding for this project was received from the College of Health and Human Services at Western Kentucky University and the Kappa Theta Chapter of Sigma Theta Tau International Honor Society of Nursing.

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### Abstract

The purpose of this project was to determine if colorectal cancer (CRC) screening education and community access to fecal occult blood tests (FOBT) is associated with an increase in the uptake of FOBT in an old order Mennonite community. Utilizing a modified cultural model, an educational offering on CRC screening and access to FOBT in the community was delivered to a self-selected sample of age-eligible participants. Thirty-three age eligible residents completed the CRC screening questionnaires and received education on CRC screening. Twenty-nine of the age-eligible participants were found to be at average risk and twenty-three elected to receive FOBT testing kits. The most commonly reported previous CRC screening was colonoscopy; however, only 30% of the population had completed any previous CRC screening. This project was successful in increasing the uptake of FOBT in an old order Mennonite community through the provision of culturally appropriate education and the delivery of FOBT within the community using a modified cultural model. If the high FOBT uptake is maintained in other OOM/Amish populations FOBT is a viable CRC screening tool in these populations.

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## **Executive Summary**

The conservative Mennonite and Amish communities are among the most rapidly growing populations in rural Kentucky and currently number more than 10,000 (Young Center for Anabaptist & Pietist Studies, 2008). In the United States (US) colorectal cancer (CRC) is the third most commonly occurring cancer and the third leading cause of cancer deaths in men and women combined (American Cancer Society, 2009a). CRC screening reduces mortality through earlier detection of polyps and cancers (Levin et al, 2008) and conservative Amish and Mennonite communities have traditionally had lower cancer screening rates (Caruso & Forman, 2007; Katz, 2005).

This project, utilizing a modified cultural model, was developed to increase CRC screening rates among members of an old order Mennonite (OOM) community. The purpose of this project was to determine if CRC screening education and community access to FOBT is associated with an increase in the uptake of FOBT in an OOM community. The goals of this project were to provide culturally appropriate education about CRC screening and to increase FOBT use in age-eligible average-risk community members. The significance of this project is in the identification of successful strategies to increase CRC screening specifically fecal occult blood testing screening in an OOM population.

The target population was a self-selected sample of men and women from an OOM community in south central Kentucky. A paper and pencil questionnaire including demographic items, last visit to a health care provider for a check-up, CRC risk assessment, and the participant's previous CRC screening behaviors was administered to the participants. All average risk age-eligible participants were offered FOBT. Data

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were analyzed using the Statistical Package for the Social Sciences, version 17 and were analyzed using means, frequency distribution, and chi square analysis.

Thirty-three age eligible residents completed the CRC screening questionnaires and received education on CRC screening. Twenty-nine of the age-eligible participants were found to be at average risk and twenty-three of these participants elected to receive FOBT testing kits. The most commonly reported previous CRC screening was colonoscopy; however, only 30% of the population had completed any previous CRC screening. One participant had completed FOBT testing prior to the project and 21 participants completed FOBT during the project, with a proportional increase of 60% of FOBT in this OOM population.

This culturally appropriate project was successful in increasing the uptake of FOBT in an OOM community. The provision of culturally appropriate education and the delivery of FOBT within the community decreased one barrier to its utilization. CRC is the third most common cancer in the US. Annual high sensitivity FOBT is one strategy recommended for the detection of CRC that is simple, minimally harmful, and relatively inexpensive. If the high FOBT return rate occurs in other OOM/Amish populations FOBT is a viable CRC screening tool in these populations. However, only the appropriate follow-up of positive FOBTs and annual FOBT will result in the reduction of CRC mortality. Further study is needed to understand the relationship between the OOM religious beliefs, cancer screening and the OOM's use of cancer screening tests.

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### Colorectal Cancer Screening in an Old Order Mennonite Community

The conservative Mennonite and Amish communities are among the most rapidly growing populations in rural Kentucky and currently number more than 10,000 (Young Center for Anabaptist & Pietist Studies [Young Center], 2008). Collectively referred to as Anabaptists, the old order Mennonites and Amish share a common religious heritage and have many similarities (Bender, Friedman, & Klaaseen, 1990). The term “old order” refers to Mennonite and Amish populations that follow a conservative lifestyle avoiding many modern technologies (Kraybill & Hurd, 2006).

In the United States (US) colorectal cancer (CRC) is the third most commonly occurring cancer and the third leading cause of cancer deaths in men and women combined (American Cancer Society, 2009a). CRC incidence rates in the US as compared to Kentucky are 52.2 and 59.3 per 100,000 and CRC mortality rates are 18.8 and 22.0 per 100,000 respectively (National Cancer Institute, 2008). Data from the adult Amish of Holmes County, Ohio indicate a lower overall cancer incidence rate (Westman et al., 2009). This settlement is the largest Amish population in the world (Young Center, 2009). CRC screening reduces mortality through earlier detection of polyps and cancers (Levin et al, 2008) and conservative Amish and Mennonite communities have traditionally had lower cancer screening rates (Caruso & Forman, 2007; Katz et al.,2005).

This project, utilizing a modified cultural model, was developed to increase CRC screening rates among members of an old order Mennonite (OOM) community. A researcher modified questionnaire was administered to elicit the prevalence of CRC screening behaviors in this community. The project was evaluated by the measurement of fecal occult blood testing (FOBT) uptake following the delivery of CRC screening

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education and community access to FOBT kits by age-eligible average risk participants. This project was partially funded by an internal faculty research grant of \$1065 from the Western Kentucky University College of Health and Human Services. The investigator also received research funds from the Kappa Theta Chapter of Sigma Theta Tau International Nursing Honor Society in the amount of \$250.00.

### **Goals**

The purpose of this project was to determine if CRC screening education and community access to FOBT is associated with an increase in the uptake of FOBT in an OOM community. The goals of this project were to provide culturally appropriate education about CRC screening and to increase FOBT use in age-eligible average risk community members.

### **Significance**

The significance of this project is in the identification of successful strategies to increase CRC screening specifically fecal occult blood testing screening in an OOM population. Preventing CRC and reducing mortality is largely dependent on screening and early diagnosis with approximately 70% of CRC cases occurring in average risk individuals (Lieberman, 2006). The successful implementation of this culturally appropriate CRC screening project could provide a framework for implementation of other cancer screening programs in these OOM communities.

### **Assumptions**

This project was based on many assumptions. Cultural competence is a process, that is ongoing, and not an outcome. Cultural competence is a critical component in the delivery of effective health care services in an OOM community. The project

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participants accurately self-reported the data on colorectal cancer screening utilization. Finally, a reduction in CRC mortality is dependent on the participant's follow-up of a positive FOBT with a diagnostic colonoscopy.

### **Problem Description**

In 2006, 59.8% of US adults reported having had a FOBT within the last year, or a structural exam (sigmoidoscopy or colonoscopy) in the preceding 10 years with Kentucky reporting a slightly lower percentage of 58.7% (American Cancer Society, 2009b). Although the screening rates for CRC in the general population have improved there continue to be medically underserved populations in rural Kentucky such as the OOMs. There are no colorectal cancer screening statistics available for the OOMs; however, in the Ohio Amish, only 12.5% reported a FOBT test within the last one year or an endoscopy within the last five years versus 28.2 of the non-Amish population (Katz et al., 2005).

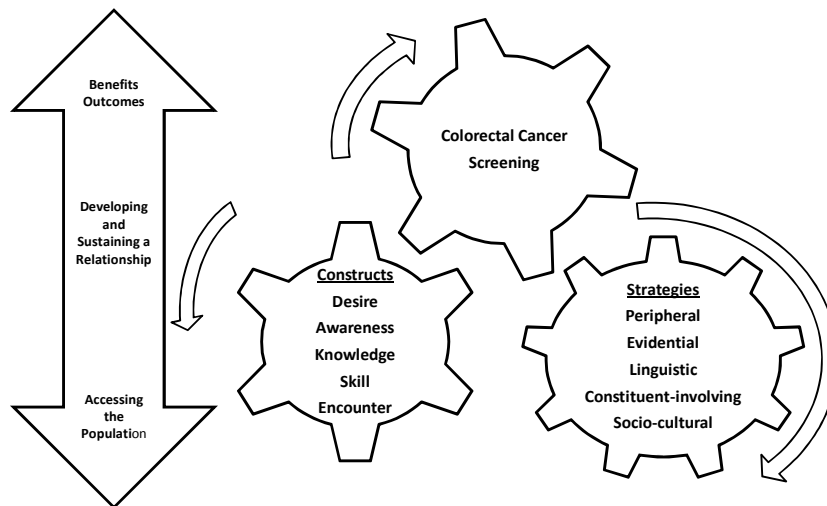
### **Model Development**

A modified cultural model was developed for this project (see Figure 1). The effective delivery of any project in an OOM community is dependent on its cultural appropriateness. The constructs contribute to the health care provider's ability, openness, and flexibility in delivering a project that is culturally appropriate (Suh, 2004). The strategies are those commonly used for enhancing cultural appropriateness in health promotion programs (Kreuter, 2003). In this project, the participant's compliance with FOBT is the health outcome. The constructs underlying cultural competence, the strategies for cultural appropriateness, and colorectal cancer screening are depicted as gears. The five identified constructs are the foundation for all of the strategies however;

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one or more strategies may be more or less appropriate and different strategies may be useful in the three model phases.

*Figure 1.* Modified cultural model



### **Constructs**

The major constructs were adapted from the Process of Cultural Competence in the Delivery of Healthcare Services developed by Campinha-Bacote (1999). This model supports the community as the teacher, cultural competence as a process that is ongoing, and requires health care practitioners to see themselves as “becoming culturally competent rather than being culturally competent”(Campinha-Bacote, p. 203). It differs conceptually from those models that define cultural competence as an end-point. The major constructs of the model include cultural desire, cultural awareness, cultural knowledge, cultural skill, and cultural encounters (Campinha-Bacote).

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Campinha-Bacote defines cultural desire as the motivation of the health care provider “to want to, rather than have to, engage in the process of becoming culturally aware, culturally knowledgeable, culturally skillful, and familiar with cultural encounters” (Campinha-Bacote, 2002, p. 182). Cultural desire is the foundation that motivates health care providers to develop cultural awareness, obtain cultural knowledge, practice cultural skills, and seek cultural encounters (Campinha-Bacote, 2002).

Self-examination and the exploration of one’s own background, both culturally and professionally are integral to the process of cultural awareness. Cultural awareness involves the recognition of one’s biases and assumptions about differing cultures and the process of becoming sensitive to the values, beliefs, and practices of another culture (Campinha-Bacote, 2002). The construct of cultural knowledge is a process of acquiring knowledge concerning health beliefs and cultural values of a client or culture, understanding of the worldview of a client or culture, and their interpretation of health and illness. Additionally, the health care provider must acquire knowledge regarding specific physical, biological, and physiological variations among in other ethnic groups (Campinha-Bacote). Cultural skill, defined as the facility to collect relevant information related to presenting problems, health histories, and physical assessment, is necessary to formulate an accurate diagnosis in ethnically diverse clients (Campinha-Bacote). Cultural encounter is the process of face-to-face contact with clients of culturally diverse backgrounds. This direct interaction will assist in modifying the existing beliefs of the provider concerning the cultural group (Campinha-Bacote). These constructs are interdependent and work in conjunction with the following cultural strategies.

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### **Strategies**

There are many common strategies for enhancing the cultural appropriateness of health care projects. Peripheral strategies, identified as packaging materials that will appeal to a certain group include the visual style of health education materials; this packaging, perceived instinctively can create interest, establish credibility, and enhance the acceptability of the message (Dyer, et al., 2005; Kreuter, et al., 2002). Evidential strategies attempt to increase the perceived relevance of a health issue for an individual or group. The perception that a problem affects others in the community can stimulate preventive action (Kreuter et al.). Constituent-involving strategies derive their support from members of a target group. These members through participation, acting as role models, and performing lay activities assist with the adoption of health promotion activities (Kreuter, et al.). Socio-cultural strategies involve the recognition of a cultures' values, beliefs, and behaviors (Kreuter, et al.). Linguistic strategies utilize the language or common words in the language of the target group (Kreuter, et al.).

### **Model Phases**

These constructs and strategies as noted previously are utilized throughout this project during the following project phases.

**Accessing the Community.** Actions that facilitate gaining access to a community include making visits to the community, socializing, conducting informal interviews, and collaborating in community events (Suarez-Balcazar, Harper, & Lewis, 2005). The use of an insider can also be helpful as an insider has access to privileged information and an awareness of the community's social context (Lee & Winters, 2006). These actions are supported by the construct of cultural desire. Cultural desire includes a



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passion for the process of cultural competence and in many cases is the impetus for work with a different cultural or ethnic group.

**Developing and Sustaining a Relationship.** Developing and sustaining a collaborative relationship is based on developing trust, adequately communicating, respecting diversity, developing a culture of learning, and respecting the cultural setting (Suarez -Balcazar, Harper, & Lewis, 2005). The constructs of the model that support these include cultural awareness, cultural skill, cultural encounters, and cultural knowledge.

**Benefits and Outcomes.** The benefits and outcomes of culturally appropriate health care are improved communication, increased trust and improvements in health care (Campinha-Bacote, 2002; Suarez-Balcazar et al., 2003). Health care providers that practice culturally appropriate health care can enhance patient outcomes and increase patient satisfaction with their health care (Suh, 2004).

### **Review of Literature**

#### **Old Order Mennonites and CRC**

The Mennonites are genetically distinct and most are Caucasian (Orton et al., 2008). In Caucasians, the incidence rate for colorectal cancer is 60.4 per 100,000 for men and 44.0 per 100,000 for women (Ries et al., 2007). There is little data available for the Mennonite or Amish communities concerning the incidence for colorectal cancer. Troyer (1988) in a review of four religious sects found that the incidence of colorectal cancer among the Amish as compared to non-Amish is slightly reduced. Melton et al. (2006) noted that the three leading causes of death (heart disease, cancer, and stroke) in a large Mennonite population were analogous to the larger US population. Westman et al.

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(2009) found that the estimated age-adjusted cancer incidence rate for non-tobacco-related cancers (including CRC) in the Ohio Amish was 72% of the age-adjusted non-Amish adult rate in Ohio.

### **Mennonite Theology and Health Care**

The roots of the Mennonite and Amish religions can be traced to the Anabaptist movement that occurred during the Protestant Reformation in the sixteenth century. The term Anabaptist, literally meaning rebaptizers, resulted from criticism of the Anabaptist's practice of performing baptism on adults who had been previously baptized as infants (Friedman, 1973). The Anabaptist reformers adopted beliefs that were antithetical to both the Catholic Church and the new Protestant doctrine and suffered persecution as a result. The original beliefs of the Anabaptists included baptism of believers (adult baptism), separation from the world, and separation of church and state (Kraybill and Hurd, 2006). The Anabaptist groups have splintered over time, and are named for the leaders in their religion including Menno Simmons (Mennonites) and Jakob Amman (Amish). While variations exist in Mennonite communities these conservative beliefs continue to influence the lifestyles and health care of many in this OOM community.

The OOMs adhere to a conservative doctrine of beliefs and practices (Kraybill & Hurd, 2006) and the core values of the community members are based on this doctrine (Hostetler, 1980). Their reliance on the horse and buggy for local transportation is central to their desire for separation from the world (Wenger, 2003) and this control of mobility emphasizes the adherence to this doctrine. One Mennonite community member stated, "if we run around we will give up what we are trying to preserve" (Kraybill & Hurd, p. 89). The OOMs do selectively modernize, using some technology in their work

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site such as cell phones (Wenger, 2003); however, they still avoid telephones or electricity in their homes (Kraybill & Hurd).

The OOMs/Amish live in a slower-paced world filled with face-to-face socialization and daily interaction with their neighbors (Graham & Cates, 2002). The impetus for most adults in this community for seeking health care is the interference of a current illness with their ability to work (Armer & Radina 2006; Fisher, 2002). These actions demonstrate two further core values the importance of community and a commitment to physical labor (Graham & Cates). Most of the OOMs speak Pennsylvania German as their primary language and English as their second language. Pennsylvania German, more popularly known as Pennsylvania Dutch is spoken to each other, in their homes, and during religious services (Kraybill & Hurd, 2006).

Health insurance or any government aid is seen as worldly and antithetical to separation from the world, implies an unwillingness to accept God's will, and is antagonistic to mutual aid (Gingrich & Lightman, 2006; Greksa & Korbin, 2004). The majority of the OOMs do not participate in health insurance programs or accept any government sponsored programs (Kraybill & Hurd, 2006). An individual's medical expenses are paid first by the family, then by the church district, and in some cases by mutual aid societies (Donnermeyer & Friedrich, 2006). The belief, that God determines health and illness in an individual is common in the OOMs/Amish communities (Drabowska, 2007; Wenger, 2003) and the community members are very accepting of debilitating conditions.

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### **Colorectal Cancer Lifestyle Risk Factors**

The lifestyle risk factors for colorectal cancer (CRC) include obesity (Moghaddam, Woodward, & Huxley, 2007), a diet high in red meat or processed meat (Gonzalez et al., 2006), an inadequate intake of fruits or vegetables (Terry, Giovannucci, & Michels, 2002), heavy alcohol consumption, smoking (Poynter et al, 2009) and physical inactivity (Wolin et al., 2009). The Amish Family Diabetes Study found that the mean body mass index (BMI) in all age groups was comparable with the US Caucasian population (Hsueh et al., 2000). More recently in a study of the Amish and non-Amish in Ohio, the BMI in women was higher in the Amish women (30.1) than the non-Amish women (29.2) (Carter, 2008). Dietary studies in the Mennonites have shown that they consume a diet high in total fat, saturated fats, and cholesterol (Glick et al., 1998). In a recent study of Amish and non-Amish communities in Northern Ohio, the Amish were found to ingest more high fat and energy dense foods (Carter). Interestingly, the comparison non-Amish group reported ingesting more servings of vegetables.

The consumption of alcohol in the old order OOMs/Amish communities is discouraged but not strictly taboo (Kraybill & Hurd, 2006). In a study of Ohio Amish approximately 55% of the men reported drinking less than or equal to one drink per week versus 16% of the non-Amish men (Carter, 2008). Smoking is also discouraged, and the reported use is less than the general US population (Blair & Hurst, 1997). The prevalence of tobacco use among Amish men in Holmes County, Ohio was measured both by self-report and a biochemical marker of nicotine exposure and was found to be 17.6% versus 32.2% for the general US population (Ferketich et al., 2008).

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### **Recommended Screening**

The American Cancer Society (ACS) recommends that the screening for CRC in average risk individuals begin at age 50. Any of the following guidelines are recommended: yearly fecal occult blood test (FOBT) with sensitivity for cancer greater than 50%, flexible sigmoidoscopy every five years, a combination of yearly high sensitivity FOBT and flexible sigmoidoscopy every five years, colonoscopy every 10 years or barium enemas every five years (ACS, 2009a). FOBT, a colorectal screening option that primarily detects cancer (Levin et al., 2008), is cost-effective (Fisher, Fikry, & Troxel, 2006) and has the potential to screen many more individuals than other CRC screening methods. In a review of four randomized controlled trials the participants allocated to a screening FOBT had a 16% reduction in the relative risk of CRC mortality (Hewitson et al., 2007) and several large randomized controlled trials of FOBT have reported a reduction in colorectal cancer mortality ranging from 15% to 33% (Bond, 2006). There is good evidence that periodic fecal occult blood testing reduces mortality from colorectal cancer (Hewitson et al., USPSTF, 2002). Additionally, all of the major trials showed that individuals with screen-detected cancers had a greater survival potential as the colorectal cancers were detected at an earlier stage.

The Hemoccult Sensa® is a high sensitivity FOBT with a sensitivity of 79.4% and a specificity of 86.7% for CRC (Whitlock et al., 2008). Although, the Hemoccult Sensa® is primarily used to detect cancer it does have a sensitivity of 41.3% and a specificity of 87.5% for advanced adenomas (Whitlock). More recently, the American Cancer Society, the US Multi-Society Task Force on CRC, and the American college of Radiology have recommended in a joint guideline annual high sensitivity FOBT as one

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option for CRC screening (Levin, et al., 2008).

### **OOM Culture and the Modified Cultural Model**

The acceptance of any project in the Mennonite community is dependent on its cultural appropriateness. The following literature supports the phases of the modified cultural model in OOM populations.

**Accessing the community.** The Old Order societies are described as a high context culture and community members “share many cultural life-ways, have much intergenerational knowledge, use many covert communication cues, and readily distinguish insiders from outsiders” (Wenger, 1995, p. 4). Other major contextual features include intergenerational responsibility, authority that is centralized, and long-term relationships (Greksa & Korbin, 2004; Kraybill & Hurd, 2006). Many OOM communities have lay midwives that deliver children in the home and provide general health advice (Hewner, 1997). Trust is a major issue in working with the Amish and without trust the Amish would not use the modern healthcare system (Greksa & Korbin, 2004; Rearick, 2003). Currently, there are few Mennonite or Amish professional health care providers and the OOMs/Amish must seek health care from outside providers. Access to these communities is more likely when the community members desire a health care service. Amish community members value including the family in care, giving the patient and family a voice, and denoting genuine caring (Blair & Hurst, 1997).

**Developing and sustaining a relationship.** To ensure culturally appropriate health care in OOM/Amish communities developing cultural awareness, obtaining cultural knowledge, practicing cultural skill, and seeking cultural encounters are necessary. Cultural knowledge of the OOM/Amish communities includes their

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worldview, health care beliefs, and religious beliefs. The worldview of these conservative Anabaptists is characterized by collectivism, self-sufficiency, and mutual assistance (Gingrich & Lightman, 2006). Community is central to the culture and the needs of the community supersede those of the individual (Wenger, 2003). Old Order Amish community members are more likely than the mainstream US population to rely on the views of both the family and community when deciding on a health care option (Dellsega, et al., 1999). Additionally, if they do seek medical care it is for acute and chronic health problems not services related to health promotion or disease prevention (Gingrich & Lightman, 2006).

Cost is another factor that discourages screening for any type of cancer. The OOMs/Amish are willing to travel great distances to receive less costly care and visit clinics in Tijuana, Mexico for surgical procedures and imaging studies (Moss, 2005). If needed the community members utilize local health care providers, are admitted to local hospitals, and pay privately for their health care (Franson, 2005). In many old order communities reduced health care costs are negotiated with local health care providers and facilities (Anand, 2008), and community members participate in mutual aid societies for more costly health care (Gingrich and Lightman, 2006).

Amish patients have also identified that they value honesty concerning health care options and respect for their decisions (Dellasega et al., 1999). Qualitative interviews with Amish community members reveal that to obtain an accurate history questions must be asked in a gentle and nonjudgmental manner (Rearick, 2003). The ability to respect decisions that conflict with one's own cultural values and to elicit information in a nonjudgmental manner is a cultural skill. Further, without seeking cultural encounters

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the provider will be unable to develop this skill. Community researchers in an Old Order Amish community found that an individual's ability and usefulness to the community "must be earned rather than assumed on the basis of credentials or professional status" (Gingrich & Lightman, 2004).

**Strategies.** In an indigenous Hawaiian population a culturally appropriate intervention utilizing socio-cultural, peripheral, and constituent involving strategies was more effective than an intervention based on social learning theory in increasing CRC screening uptake (Braun, et al., 2004). The "Screen for Life" brochure, a basic educational pamphlet on colorectal cancer screening methods, has been preferred and recommended in other rural and low literacy populations (Davis et al., 2006) was chosen for this project as most of the OOMs are educated through the eighth grade. The conservative OOMs/Amish consider photographs an unacceptable form of pride and do not allow pictures (Kraybill & Hurd, 2006) and the "Screen for Life" brochure incorporates only simple drawings.

**Benefits and outcomes.** Health fairs and safety programs held in the community have demonstrated success by maintaining sensitivity for the transportation of community members (Graham & Cates, 2006). The Task Force on Community Preventive services found that the removal of structural barriers is recommended to increase the use of cancer screening and removing these barriers has been accomplished through change in location, hours of operation, and availability of childcare (USPSTF, 2001). Traditionally the OOMs/Amish have not engaged in preventive care however, some communities have recognized the benefits of preventive care particularly with immunizations (Greksa & Korbin, 2004). In recent years, the OOM/Amish communities have increased their



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participation in preventive screenings (Caruso & Forman, 2007; Dincher, 2007).

Community members are willing to see their health care providers for elevated blood pressure, glucose, and lipid levels to obtain appropriate follow up and treatment (Caruso & Forman, 2007). These Anabaptist community members have a high level of interest in health care and both the Mennonite and Amish newsletters contain regular columns on health remedies, accidents, and illnesses (Wenger, 1995).

### **Design of the Project**

#### **Goals**

The purpose of this project was to determine if CRC screening education and community access to FOBT was associated with an increase in the uptake of FOBT in an OOM community. The goals of this project were to provide culturally appropriate education on CRC cancer screening to adult community members and to increase FOBT use in age-eligible average risk old order community members.

#### **Project Objectives**

The following objectives were defined for the project:

1. Describe the baseline prevalence of CRC screening behaviors in CRC average risk and CRC above average risk community members age 50 to 75 years.
2. Deliver culturally appropriate group health education on CRC screening to 100 community members.
3. Distribute FOBTs to 50 age-eligible average risk OOM community members.
4. Increase by 20% the proportion of average risk adults aged 50 to 75 years who have completed FOBT testing
5. Determine the compliance with follow-up investigations for those who test

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positive for FOBT.

### **Study Questions**

1. What is the prevalence of CRC risk factors in age eligible OOM community members?
2. What is the prevalence of CRC screening behaviors in age-eligible average risk and age-eligible above average risk OOM community members?
3. What is the proportional increase in the uptake of fecal occult blood testing following a culturally appropriate educational intervention?
4. What is the compliance with follow-up investigation for OOM community members with positive FOBTs?

### **Project Description**

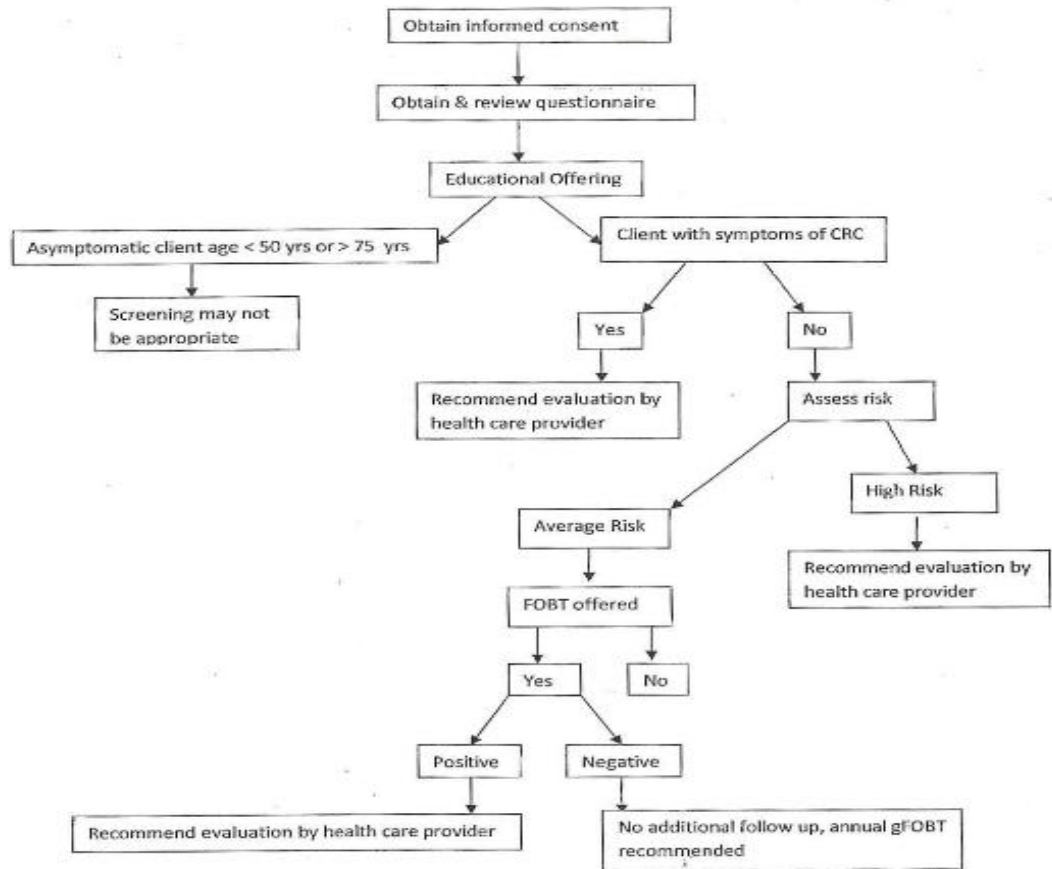
Following Institutional Review Board (IRB) approval from the University of Kentucky and Western Kentucky University informed consent was obtained from participants. The project was designed using the following study procedures:

1. A researcher modified paper and pencil questionnaire was administered to each participant. The questionnaire requested demographic items, last visit to a provider for a checkup, CRC risk assessment, and the participant's previous CRC screening behaviors (see Appendix A). The project screening algorithm is displayed graphically (see Figure 2).
  - a. Data were collected by self-report from the participants and with 60% of the participants the investigator verbally asked the items and recorded the responses.

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- b. Data were obtained during a visit to the regular clinic day or at the request of the participant in their home or work site.
  - c. Participation in the project did not necessitate the participant see the physician in the clinic.
2. The investigator reviewed the questionnaire for risk stratification.

Figure 2. Flow of project participants



1. Following risk stratification individuals at above average risk due to a history of adenomatous polyps; a personal history of CRC; a family history of either CRC or colorectal adenomas diagnosed in a first-degree

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relative before age 60 years; or a high risk due to a history of inflammatory bowel disease were referred to their health care provider.

2. The educational session was administered to all participants and consisted of the content from the “Screen for Life Facts on CRC Screening Brochure.” A brochure with this content was given to each participant (see Appendix B). The presentation was made by the investigator and questions were encouraged.
3. All age eligible average risk participants (50 to 75 years) were given the opportunity to receive FOBT collection kits, appropriate pre-addressed barrier mailers, and asked to send the stool in for analysis within two weeks.
4. The Hemoccult Sensa® was utilized for FOBT.
5. Instructions on specimen collection, drug restrictions, and dietary restrictions prior to specimen collection were included with the kits and repeated verbally by the investigator (see Appendix F).
6. The names and addresses of participants receiving a kit were recorded in a log.
7. The processing of the FOBT was completed according to the laboratory standard practices in a moderate complexity laboratory at Western Kentucky University Health Services.
8. The FOBT results were sent by the laboratory to the investigator, who recorded them and forwarded them to the participant.

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9. The FOBT results were mailed to the participant's home and accompanied by a form letter explaining the results.
  - a. Individuals with negative FOBT were reminded that the FOBT should be repeated annually and given the dates the investigator will visit the community. The investigator was available for any further questions from the participants concerning colorectal cancer screening (see Appendix D).
  - b. Individuals with one or more positive results were referred to their health care provider. The current America Cancer Society (2009) recommendation of a full colon evaluation for follow-up of a positive FOBT was included in the letter. The follow-up evaluation was at the discretion of the primary care provider (see Appendix C).
10. Following completion of the project, a summary report was made to the Mennonite community using aggregated data.

### **Application of Model to Project Design**

The project design was based on a modified cultural model. The model phase, community characteristic/belief, culturally appropriate strategy, and project activity are summarized in Table 1.

**Accessing the community.** The initial phase of the model, accessing the community was accomplished by the investigator through collaboration with a faculty member at Western Kentucky University (WKU). This faculty member has collaborated with a lay health care provider in the community for over ten years to provide health

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education, clinic services, and is trusted members in the community. The investigator has assisted with health activities in the community such as monthly clinic days, a lipid-screening project, and other activities. The investigator and faculty member approached the Bishop of the community and received permission to offer the project in the community. Cultural desire was evidenced by the long-term partnership between the WKU faculty member, lay health care provider and other community members. Cultural desire was also demonstrated in the investigator's participation in prior clinics and previous projects.

**Developing and sustaining a relationship.** Through continued partnership with the Mennonite community, the investigator became more culturally aware of differences in culture. Cultural knowledge including the reliance on community views concerning health care options and lack of perceived need were considered when choosing the group format for the CRC screening educational offering. The investigator believed this would encourage other community members to engage in CRC screening. The items pertaining to CRC screening were chosen because each of the procedure questions was prefaced by a description of the procedure. The lay health care provider and another community member reviewed the CRC screening questionnaire prior to its distribution. The format of the questionnaire in including the procedure explanations was seen as helpful in a population that has little exposure to health care. The "Screen for Life" Brochure was chosen because of its acceptance in other rural and low literacy populations, lack of pictures, and emphasis on CRC prevention. Two members of the community for cultural appropriateness reviewed the brochure.

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Table 1.

*Model Phase, community characteristic/belief, type of strategy and activity*

Model Phase	Community Characteristic/Belief	Strategy	Activity
Accessing	Trust of outsiders must be developed	Socio-cultural	Participating in scheduled clinic days and other health care projects
Accessing	Use of lay health care provider as an insider	Constituent-involving	Coordinating the project with the lay health care provider
Accessing	Current community participation in cholesterol/glucose/BP screenings	Socio-cultural	Offering colorectal cancer screening in addition to these services
Accessing	Authority is centralized	Socio-cultural	Asking the permission of the Bishop to proceed
Developing and Sustaining	Collectivism, value the opinions of community members	Constituent-involving	CRC screening education in a group format
Developing and Sustaining	Explanatory questionnaire educational level at the 8 <sup>th</sup> grade, avoidance of pictures	Peripheral	Culturally appropriate educational materials
Developing and Sustaining	Do not have health insurance or accept government support	Socio-cultural	FOBT utilized for CRC screening
Developing and Sustaining	CRC cancer is not preventable	Evidential	Increase awareness that colorectal cancer is preventable
Developing and Sustaining	Lack of perceived need	Evidential	Incidence and prevalence in the average risk population presented in education
Benefits and Outcomes	Lack of accessibility to CRC screening	Socio-cultural	Offering FOBT in the community
Benefits and Outcomes	Compliant with diet restrictions	Socio-cultural	Decreasing the number of false positive FOBTs
Benefits and Outcomes	High level of interest in health care	Constituent-involving	CRC screening awareness increased
Benefits and Outcomes	Avoid technology, cost conscious	Socio-cultural	FOBT in home, low technology, inexpensive
Benefits and Outcomes	Preventive care not traditionally practiced	Constituent-involving	Presentation of CRC screening project findings to the community with Q & A

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**Benefits and outcomes.** FOBT was accessible to this OOM community decreasing one barrier to its utilization. Although the OOM/Amish communities reject most technology, home-administered FOBT because of its simplicity was thought to be more acceptable to them. This project partnership provided learning opportunities for health care professionals in an OOM community.

### **Study Population**

The target population was a self-selected sample of men and women from an OOM community in south central Kentucky. The inclusion criteria were: clients were living in the OOM community, at least 50 years old and not older than 75 years, and had the ability to read and write English. Participants were excluded from the FOBT portion of the study if they reported a history of adenomatous polyps, CRC, Crohn's disease, Ulcerative Colitis, Familial Adenomatous Polyposis, Non-polyposis Colon Cancer, or a family history of CRC in a first-degree relative before the age of 60 years.

### **Methods**

The project application was submitted to the University of Kentucky Institutional Review Board (IRB) and the Western Kentucky University IRB and approved by both. After approval was received, visits were scheduled in the community with the input of the WKU faculty member, lay health care provider, and other community members. The visits were scheduled on clinic days and other days when requested by community members. The lay health care provider publicized the event by word of mouth during social gatherings. Data collection using the CRC screening questionnaire occurred during the regular clinic days and prearranged visits to the homes



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and work sites of the community members. Analyses of the data were completed using mean, frequency distribution, and chi-square analysis.

### **Instrument**

A paper and pencil researcher modified questionnaire was administered. The questionnaire included demographic items, last visit to a provider for a checkup, CRC risk assessment, and the participant's previous CRC screening behaviors (see Appendix A). The participants were asked to report their height and weight. Body mass index (BMI) was calculated from this self-reported data using the following formula:  $\text{weight (lb)} / (\text{height (in)} \times \text{height (in)}) \times 703$ . A positive association has been found between an increased BMI and the risk of colorectal cancer (Harriss et al., 2009; Ning, Wang, & Giovannucci, 2009). The item, last visit to a provider for a checkup, elicited information on a usual source of care. Having a usual place of care and a provider has been consistently associated with increased odds of receiving preventive care/screening services (Blewett et al., 2008) and the OOM community members are less likely to have a source of care because of their propensity to visit a HCP only if the illness or condition is affecting their ability to work. The items pertaining to CRC screening behaviors were adapted from items developed by the Division of Cancer Control and Population Sciences of the National Cancer Institute (Vernon, et al., 2004). The self-reported colorectal cancer screening questionnaire has a sensitivity of 0.98 for overall adherence (Partin, et al., 2009).

### **Project Implementation**

As previously mentioned accessing the population was of utmost importance in this OOM community. Throughout the summer, communication with the lay health care

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provider included IRB progress and the expected date of the project. The project was implemented on August 11, 2009 during a scheduled clinic day. A scheduled clinic day includes a group presentation to the OOM community members on a health education topic chosen by the community, health screenings, and illness care. Through the lay health care provider, it was announced that education and CRC cancer screening would be offered to individuals from 50 to 75 years of age on that day. This was begun about three weeks prior to the scheduled clinic day. It was also announced that ice cream would be available in an effort to attract attention and to increase attendance on the project day.

The project investigator utilized the regularly scheduled clinic day, held in a home in the OOM community. A card table, chairs, and educational materials were placed in a corner of the home. The informed consent, educational presentation, and distribution of materials occurred in this location. Ice cream kept frozen by dry ice was available in four portable coolers on the covered porch of the home. Throughout this morning, 12 participants visited the clinic site and participated in the project. During the afternoon, the investigator visited the homes and work sites of individuals that expressed an interest in completing the CRC screening obtaining five more participants and received referrals for other family and friends. The remaining participants either presented on the following two clinic days or were visited in their home or work site in the community. The investigator traveled to the community on five separate occasions.

Following written notification from the laboratory at Western Kentucky University Health Services, the investigator generated and mailed the appropriate notification letter. All collected data and FOBT results were recorded in a database in the

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Statistical Package for the Social Sciences (SPSS). On December 8, 2009, a report was made to the OOM community. The report included the current CRC screening guidelines, number of project participants, demographic and statistical results of the project in aggregate, and a period of questions and answers.

### **Data Analysis**

Data were analyzed using the Statistical Package for the Social Sciences, version 17 and descriptive statistics were reported. The percentage of age-eligible average participants that completed FOBT were reported. The prevalence of each risk factor and prior screening experience were reported using frequency distributions for these variables. The comparison of prior screening experience (i.e., yes/no to prior screening for colorectal cancer) between those with and without one or more risk factors was calculated using the chi-square test of association.

### **Resources**

The members of this OOM community were the largest resource and this project would not have been possible without their voluntary participation. Other resources included a Western Kentucky University (WKU) School of Nursing faculty member, WKU Health Services Laboratory and staff, a password protected computer in the investigator's office to ensure confidentiality, SPSS software, and a printer. This project was conducted from June 28, 2009 through October 27, 2009 with a final report delivered to the OOM community on December 8, 2009.

### **Project's Expected Measurable Outcomes**

This study had several measurable outcomes. The first outcome was the number of community members that completed the CRC screening questionnaire. The second

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outcome was the number of participants that received CRC screening education. The third and fourth outcomes were the number of FOBTs kits distributed and the number of FOBTs returned. The last measurable outcome was the number of positive FOBTs and the number of project participants who completed the recommended follow-up.

### Findings

Thirty-seven participants completed the CRC questionnaire; however, four of these participants did not meet the age criteria. Thirty-three age eligible residents completed the CRC screening questionnaires and received education on CRC screening. This Mennonite community published a community directory in February 2009 listing the residents, birth dates, marriage dates, children living at home, and addresses. Currently, in this community there are 59 residents between the ages of 49 and 76 years (Old Order Mennonite Communities, 2009). Approximately 56% of the age-eligible population participated in the project.

In the population, demographic data indicated there was a nearly equal gender mix of men and women. The age of the participants ranged from 50 to 75 years with a mean age of 61 years and mean BMI of 26.5 (see Table 2). A majority of the sample was married (see Table 3). In this community, 27% of men and 30% of women had not visited a health care provider in the last 12 months.

Table 2

#### *Mean Age and Mean BMI of Participants by Gender*

Measure	Men	Women	All
Age	61.1	60.9	61.0
BMI	24.3	28.6	26.5

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Table 3

*Individual Characteristics of the Participants*

	Men		Women		All	
	# of pts	%	# of pts	%	# of pts	%
<b>Marital Status</b>						
Single	2	6%	1	3%	3	9%
Married	14	42%	15	45%	29	87%
Widow/Widower			1	3%	1	3%
<b>Last Visit to a HCP</b>						
Within 6 mo	5	15%	4	12%	9	27%
6 mo to 1 year	2	6%	3	9%	5	15%
1 – 2 years	5	15%	2	6%	7	21%
2 – 5 years	1	3%	4	12%	5	15%
More than 5 years	2	6%	4	12%	7	21%
Never	1	3%	0		1	3%

### Study Questions

**Study Question One.** What is the prevalence of CRC risk factors in age eligible old order community members?

The risk factors for CRC are shown in Table 4. The most common risk factor for CRC identified by the participants was a first degree relative with CRC. Women were more likely to report a risk factor for CRC than men. Twelve percent of the participants reported a risk factor for CRC.

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Table 4

*Risk Factor Prevalence for CRC in an Old Order Mennonite Community (N=33)*

Risk Factor	<u>Men</u>		<u>Women</u>		<u>All</u>	
	# of pts	%	# of pts	%	# of pts	%
CRC History	0		0		0	
Polyps	0		1	3%	1	3%
Crohn's Disease	0		0		0	
Ulcerative Colitis	0		1	3%	1	3%
1 <sup>st</sup> ° Relative with CRC	1	3%	1	3%	2	6%
FH of FAP* or NPCC*	0		0		0	
Any Risk Factor	1	3%	3	9%	4	12%

\*Familial Adenomatous Polyposis      \*\*Non-polyposis Colon Cancer

**Study Question Two.** What is the prevalence of CRC screening behaviors in age-eligible average risk and age-eligible above average risk community members?

There were 59 age-eligible members in the community and of this population, 33 completed the CRC screening questionnaire. Twenty-nine (87%) of the surveyed population were categorized as average risk and four (12%) were found to be above average risk. A chi-square analysis was completed to compare the differences in the frequency of screening between the average risk participants and the above average risk participants. The chi-square analysis demonstrated there was a significant difference in screening behavior between the average risk and above average risk patients. Of the total population, the percent of average risk patients was 88% (29 of 33) and of those average

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Table 5

*Previous Colorectal Cancer Screening History by Gender*

CRC Screening	<u>Men</u>		<u>Women</u>		<u>All</u>	
	# of pts	%	# of pts	%	# of pts	%
FOBT	1	3%	0		1	3%
Sigmoidoscopy	1	3%	1	3%	2	6%
Colonoscopy	4	12%	3	9%	7	21%
Total	6	18%	4	12%	10	30%

risk patients 21% had complete some type of CRC screening in the past. The percent of participants that were above average risk for CRC was 12% (4 of 33) and 75% of these participants had completed CRC screening in the past (see Table 6). The above average risk participants were much more likely to have had previous CRC screening. Men were

Table 6

*Prevalence of Past CRC Screening Reported by Average Risk and Above Average Risk Participants (N=33)*

Risk	<u>Previous CRC Screening</u>		<u>No Previous CRC Screening</u>		<u>Chi-Square Values</u>	
	# of pts	%	# of pts	%	X <sup>2</sup>	p value
Average	6	21%	23	79%	5.227	.022
Above Average	3	75%	1	25%		

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somewhat more likely to have participated in previous CRC screening. The most commonly reported previous CRC screening was colonoscopy (see Table 5).

**Study Question Three.** What is the proportional increase in the uptake of fecal occult blood testing following a culturally appropriate educational intervention?

Twenty-three of the participants were at average risk and received FOBT testing kits. The proportion of these average risk participants that returned the FOBT for testing was 91.3% (21 of 23). Of the 33 participants, one participant had completed FOBT testing prior to the project and 21 participants completed FOBT following education and distribution of the FOBTs in the community. This was a proportional increase in the uptake of FOBT of 60 percent. Following this project of the population that participated 85% (28 of 33) were up-to-date with CRC screening. Among the total age-eligible population in this community, 48% were up-to-date with CRC screening.

**Study Question Four.** What is the compliance with follow-up investigations for community members with positive FOBTs?

Three of twenty-one FOBTs completed were positive for occult blood. To date one participant has completed the recommended follow-up with a colonoscopy during which the participant was found to have multiple polyps. A second participant completed a second round of FOBT and a third participant has not pursued any diagnostic evaluation. Therefore 66% (2 participants) were compliant with a follow-up investigation; however, only 33% (1 participant) received the recommended follow-up for a positive FOBT, a colonoscopy.



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### **Summary**

Thirty-three age eligible residents completed the CRC screening questionnaires and received education on CRC screening. Twenty-nine of the age-eligible participants were found to be at average risk and twenty-three elected to receive FOBT testing kits. The most commonly reported previous CRC screening was colonoscopy; however, only 30% of the population had completed any previous CRC screening. One participant had completed FOBT testing prior to the project and 21 participants completed FOBT during the project, with a proportional increase of 60% in this population.

The 2008 National Health Interview Survey found that 26% of US men and 12% of US women had no visits to a health care provider in 12 months (U. S. Department of Health and Human Services, 2009). In this OOM population, 27% of men and 30% of women had not visited a health care provider in the last year decreasing their chances of receiving preventive and/or cancer screening services. In this population, the return rate for the FOBT was 91%. Other studies in all populations have demonstrated a median return rate of 40.0 to 50.0% (Stokamer et al., 2005).

### **Fiscal and System Impacts of the Project**

The fiscal impacts of this project are significant. In 2009, an estimated 49,200 deaths will occur in the total US total population from colorectal cancer (ACS, 2009b). An economic analysis of colorectal cancer screening indicates that all CRC cancer screening strategies deliver an additional year of life for a cost of less than \$40,000. However, when the CRC screening strategies are compared to each other the results are more complex. In some models, FOBT is the most cost-effective and in some models, colonoscopy is the most cost-effective (Pignone, Russell, & Wagner, 2005). The use of

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annual FOBT in unscreened average risk individuals has the potential to screen an estimated 3,000,000 more Americans for far less money than colonoscopy (Fisher, Fikry, & Troxel, 2006).

The direct costs of this project per individual were \$71. Other similar projects have demonstrated similar costs with a ranging from \$42 to \$200. Any increase in the number of colonoscopies or other structural examinations would increase the OOM nonmedical costs also. The nonmedical costs of colorectal cancer screening with FOBT versus colonoscopy are significantly less, \$35 versus \$308 (Heitman, et al., 2008).

The potential fiscal impact on the OOM population is large as they pay out-of-pocket for their health care. FOBT false positives will result in further unnecessary testing to rule out disease. Although the OOMs would negotiate for and would expect discounted colonoscopy, any false positive FOBT, and the recommended follow-up diagnostic testing would increase their overall health care costs. Not only would the procedure have been costly but also, the nonmedical costs would have been significant. Since the OOMs do not drive cars, travel for follow-up diagnostic testing would involve long travel times and/or the cost of hiring a driver. Also, any time spent in travel is time away from their work and if they do not work they do not have income.

### **The Project Model**

The project, implemented during a scheduled clinic day was coordinated with the OOM lay health care provider. Two community members reviewed the CRC screening questionnaire and educational offering content/brochure for understandability and cultural appropriateness prior to its administration. The CRC screening education was delivered in a community setting that was both comfortable and familiar to the

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community members. Although not delivered in a large group format it was completed in small groups. FOBT, offered in the community decreased one barrier to its use and provided access to its utilization.

### **Evaluation of Project**

#### **Objectives/Research Questions**

This project was developed to increase CRC screening rates among members of an old order Mennonite (OOM) community. The goals of this project were to provide culturally appropriate education on CRC screening and to increase FOBT use in age-eligible average risk community members. Objectives 1, 4, and 5 as stated on page 20 were met. Objectives 2 and 3 as stated on page 20 were partially met due to initial inaccurate population estimates. The initial population estimate of the community was 500 people (Young Center for Anabaptist & Pietist Studies, 2008). However, it was determined after the project was begun that there were only 59 members of the community between the ages of 49 and 76 (Old Order Mennonite Communities, 2009) therefore, objectives 2 and 3 were based on population estimates that were inaccurately high. Following completion of the project, 48% of the age-eligible population were up-to-date with CRC screening. The research questions were answered from data collected from the researcher developed questionnaire, the application of frequency statistics, and Chi-square analysis.

#### **Project Limitations/Recommendations**

All participants were from an OOM community in south central Kentucky, were descended from similar ethnic backgrounds, and were Caucasian. This limits the generalizability of these results to a larger population. Additionally, most of the

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demographic data were self-reported and may have been inaccurate. Further, in some cases the investigator verbally asked the survey questions concerning colorectal cancer screening possibly introducing response bias.

In this OOM population, only one of three participants with positive FOBT received the recommended follow-up of a diagnostic colonoscopy. The second participant pursued follow-up, but was recommended to repeat a home-administered FOBT. This finding is not isolated to this population, Nadel et al. (2005) found in survey of primary care physicians that 29.7% recommended repeating a positive FOBT as follow-up. Unless positive FOBTs are evaluated with a diagnostic colonoscopy, a reduction in CRC mortality will not be realized.

This project was planned for delivery in a one day with a single educational offering and distribution of FOBTs. However, the educational component was delivered individually or in groups of two over five visits to the community and a two-month period. Many of the educational sessions and the distribution of FOBTs occurred in the participant's homes and worksites. The timing of the project may also have been less than optimal as it was delivered during the busy agricultural season for the participants. Further study is needed to understand the relationship between the OOM religious beliefs, cancer screening and their use of cancer screening tests.

### **Reflections on the Project**

As previously stated this project was the second screening effort completed in this community by the investigator. The first effort was a lipid-screening project, which received large group participation and allowed the education/screening to occur in a one-day format. However, this project implemented in the same format did not receive

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concentrated group participation. The participants seemed to be reluctant to discuss CRC cancer screening in large groups but willing to discuss in small groups or individually. Nearly all of the education on CRC screening was completed either one-to-one or in groups of two, mostly including immediate family members. The inability to utilize a large group format made the project much more labor intensive and decreased the efficiency of the project.

### **Conclusions**

This project implemented using a modified cultural model was successful in increasing the uptake of FOBT in an OOM community. The provision of culturally appropriate education and the delivery of FOBT within the community decreased one barrier to its utilization. CRC is the third most common cancer in the US. Annual high sensitivity FOBT is one strategy recommended for the detection of CRC that is simple, minimally harmful, and relatively inexpensive. If the high FOBT compliance is maintained in other OOM/Amish populations FOBT is a very viable CRC screening tool in these populations. However, only the appropriate follow-up of positive FOBTs and annual FOBT will result in the reduction of CRC mortality.

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### References

- American Cancer Society (2009a). *Cancer Facts and Figures 2009*. Atlanta: American Cancer Society. Retrieved October 3, 2009 from <http://www.cancer.org/downloads/STT/500809web.pdf>
- American Cancer Society (2009b). *Cancer Prevention & Early Detection Facts & Figures 2009*. Atlanta: American Cancer Society. Retrieved December 2, 2009 [http://www.cancer.org/downloads/STT/860009web\\_6-4-09.pdf](http://www.cancer.org/downloads/STT/860009web_6-4-09.pdf)
- Anand, G.(2008, June 28). Opting out. *The Wall Street Journal*. Retrieved April 12, 2009 from <http://online.wsj.com/article/SB121460367338511945.html>
- Armer, J. M. & Radina, M. E. (2006). Definition of health and health promoting behaviors among Midwestern old order Amish families. *The Journal of Multicultural Nursing & Health, 12*, 44-53.
- Bender, H. S., Friedmann, R., and Klaassen, W. (1990). "Anabaptism." *Global Anabaptist Mennonite Encyclopedia Online*. Global Anabaptist Mennonite Encyclopedia Online. Retrieved 07 December 2009 <http://www.gameo.org/encyclopedia/contents/A533ME.html>
- Blair, R. B. & Hurst, C. E. (1997). Amish health care. *The Journal of Multicultural Nursing and Health, 3*, 38-43.
- Blewett, L. A., Johnson, P. J., Lee, B., & Scal, P. B.(2008). When a usual source of care and usual provider matter: Adult prevention and screening services. *Journal of General Internal Medicine, 23*, 1354-1360. Retrieved from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2518015/>

## COLORECTAL CANCER SCREENING

- Bond, J. H. (2006). The place of fecal occult blood test in colorectal cancer screening in 2006: the U.S. perspective. *American Journal of Gastroenterology*, *101*, 219-21.
- Braun, K. L., Fong, M., Kaanoi, M. E., Kamaka, M. L., & Gotay, C. C. (2005). Testing a culturally appropriate, theory-based intervention to improve colorectal cancer screening among native Hawaiians, *Preventive Medicine*, *40*, 610-627, doi: 10.1016/j.upmed.2004.09.005.
- Campinha-Bacote, J. (1999). A model and instrument for addressing cultural competence in health care. *Journal of Nursing Education*, *38*, 203-207.
- Campinha-Bacote, J. (2002). The process of cultural competence in the delivery of healthcare services: A model of care. *Journal of Transcultural Nursing*, *13*, 181-184.
- Carter, G.B. (2008). Food intake, dietary practices, and nutritional supplement use among the Amish. *Unpublished Doctoral Theses: Ohio State University*.
- Caruso, N. & Forman, J. (2007, June). *Preventive Health screenings for Old Order Mennonite women*. Poster session presented at the Amish in America: New identities & diversities, Elizabethtown, PA.
- Centers for Disease Control (2007, November). Behavioral Risk Factor Surveillance System. Retrieved November 26, 2007 from <http://apps.nccd.cdc.gov/brfss/display.asp?cat=CC&yr=2006&qkey=4424&state=KY>
- Davis, R. E., Armstrong, D. K., Dignan, M., Norling, G. R., & Redmond, J. (2006). Evaluation of educational materials on colorectal cancer screening in Appalachian Kentucky. *Preventing Chronic Disease*, *3*(2), A43.
- Dellasega, C., Hupcey, J. E., & Fisher, K. (1999). Culturalizing health care for a

## COLORECTAL CANCER SCREENING

culturally diverse population: The Amish. *Clinical Excellence for Nurse Practitioners*, 3, 10-11.

Dincher, M. (2007, June). *Amish community health screenings*. Poster session presented at the Amish in America: New Identities & Diversities, Elizabethtown, PA.

Documet, P. I., Green, H. H., Adams, J., Weil, L. A., Stockdale, J., & Hyseni, Y. (2008). Perspectives of African American, Amish, Appalachian and Latina women on breast and cervical cancer screening: implications for cultural competence. *Journal of Health Care Poor and Underserved*, 19(1), 56-74.

Donnermeyer, J. E., & Friedrich, L. (2006). Amish society: An overview reconsidered. *The Journal of Multicultural Nursing & Health*, 12, 35-43.

Drabrowska-Miciula, E. (2007). A comparison of the perceptions of risk and health between old Mennonites and mainstream society in the grand river valley: A cross-cultural analysis (Unpublished Doctoral Dissertation). Retrieved November 1, 2009 from PROQUEST.

Dyer, K. J., Fearon, K. C. H., Buckner, K., & Richardson, R. A. (2005). Diet and colorectal cancer risk: Evaluation of a nutrition education leaflet. *Health Education Journal*, 64, 247-255.

Ferketich A. K., Katz M. L., Kauffman R. M., Paskett E.D., Lemeshow, S., Westman, J. A., Clinton S.K., Bloomfield C.D., Wewers M.E. (2008). Tobacco use among the Amish in Holmes County, Ohio. *Journal of Rural Health*, 24, 84-90.

Fisher, K.(2002). Lessons learned while conducting research within an Amish community. *Journal of Multicultural Nursing & Health*, 8, 21-27.

Fisher, J. A., Fikry, C., & Troxel, A. B.(2006). Cutting cost and increasing access to



## COLORECTAL CANCER SCREENING

colorectal cancer screening: Another approach to following the guidelines.

*Cancer Epidemiology, Biomarkers & Prevention*, 15, 108-113

Franson, F. J. (2005). *Markets, trust, and a culture of responsibility: Implications for a family-friendly health care policy* (Working paper No. 20/2005). International Centre for Economic Research.

Friedmann, R. (1973). *The theology of Anabaptism: an interpretation*. Scottsdale, PA: Herald Press, 1973.

Gingrich, L. G. & Lightman, E. (2006). Striving toward self-sufficiency: A qualitative study of mutual aid in an old order Mennonite community. *Family Relations*, 55, 175-188.

Glick, M., Michel, A. C., Dorn, J., Horwitz, M., Rosenthal, T., & Trevisan, M. (1998). Dietary cardiovascular risk factors and serum cholesterol in an Old Order Mennonite community. *American Journal of Public Health*, 88(8), 1202-1205.

Gonzalez, C. A. (2006). Nutrition and cancer: the current epidemiological evidence. *British Journal of Nutrition*, 96 Supplement 1, S42-45.

Graham, L. L., & Cates, J. A. (2006). Health care and sequestered cultures: A perspective from the Old Order Amish. *Journal of Multicultural Nursing & Health*, 12, 60-64.

Greksa, L. P. & Korbin, J. E. (2004). Amish. In C. R. Ember and M. Ember (Eds.). *Encyclopedia of Medical Anthropology*, (pp. 557-564). New York: Kluwer Academic/Plenum Press.

Hamman, R. F., Barancik, J. I. & Lilienfeld, A. M. (1981). Patterns of mortality in the old order Amish. *American Journal of Epidemiology*, 114, 845-861.

Harriss, D. J., Atkinson, G., George, K., Cable, N. T., Reilly, T., Haboubi, N., et al.

## COLORECTAL CANCER SCREENING

- (2009). Lifestyle factors and colorectal cancer risk (1): systematic review and meta-analysis of associations with body mass index. *Colorectal Dis*, 11(6), 547-563. Doi: 10.1111/j.1463-1318.2009.01766.x
- Heitman, S., Au, F., Manns, B., McGregor, S., & Hilsden, R. (2008). Nonmedical costs of colorectal cancer screening with the fecal occult blood test and colonoscopy. *Clinical Gastroenterology and Hepatology*, 6, 912-917. doi: 10.1016/j.cgh.2998.03.006
- Hewitson, P., Glasziou P., Irwig L., Towler, B., Watson, E. (2007) Screening for colorectal cancer the faecal occult blood test, Hemoccult. *Cochrane Database of Systematic Reviews* 2007, Issue 1. Art. No.: CD001216.
- Hewner, S. J. (1997). Biocultural approaches to health and mortality in an Old Order Amish community. *Collegium Antropologicum*, 21(1), 67-82.
- Hostetler, J. A. (1980). *Amish Society* (3<sup>rd</sup> Ed). Baltimore: John Hopkins Press.
- Hsueh, W. C., Mitchell, B. D., Aburomia, R., Pollin, T., Sakul, H., Gelder Ehm, M., et al. (2000). Diabetes in the Old Order Amish: characterization and heritability analysis of the Amish Family Diabetes Study. *Diabetes Care*, 23(5), 595-601.
- Katz, M. L., Ferketich, and Paskett, E. D., Westman, J., Lemeshow, S., Clinton, S., & Bloomfield, C. (2005). Cancer screening among Amish adults. Centers for Population Health and Health Disparities. Retrieved from <http://cihdr.uchicago.edu/Lectures/grantees/posters/Abstract%20Book.pdf>
- Katz, M. L., Ferketich, and Paskett, E. D (2007). Cancer-related lifestyle factors among the Amish and non-Amish living in Ohio Appalachia. Poster presentation American Cancer Society. Retrieved from

## COLORECTAL CANCER SCREENING

<http://cancer.confex.com/cancer/disparities/techprogram/P1198.HTM>

- Kim-Godwin, Y. S., Clarke, P. N., & Barton, L. (2001). A model for the delivery of culturally competent community care. *Journal of Advanced Nursing*, 35, 918-925.
- Kraybill, D. B., & Hurd, J. P. (2006). *Horse and buggy Mennonites: Hoofbeats of humility in a postmodern world*. University Park, PA: Pennsylvania State University Press.
- Kraybill, D. B. & Nolt, S. M. (2004). *Amish Enterprise: From plows to profits*. Baltimore, Maryland: The Johns Hopkins University Press.
- Kreuter, M. W., Lukwago, S. N., Bucholtz, D. C., Clark, E. M., & Sanders-Thompson, V. (2002). Achieving cultural appropriateness in health promotion programs: Targeted and tailored approaches. *Health Education & Behavior*, 30, 133-146.
- Lee, H. J., & Winters, C. A. (Eds.). (2006). *Rural Nursing*, New York: Springer Publishing Company.
- Levin, B., Lieberman, D. A., McFarland, B., Smith, R. A., Brooks, D., Dash, C. et. al. (2008). Screening and surveillance for the early detection of colorectal cancer and adenomatous polyps, 2008: A joint guideline from the American Cancer Society, US Multi-Society Task Force on colorectal cancer, and the American College of Radiology. *CA: A Cancer Journal for Clinicians* Retrieved on March 27, 2008 from <http://caonline.amcancersoc.org/cgi/content/full/CA.2007.0018v1>
- Lieberman, D. (2006). Screening for colorectal cancer in average-risk populations. *The American Journal of Medicine*, 119, 728-735.
- Melton, P. E., Zlojutro, M., Kimminau, K., & Crawford, M. H. (2006). Biological aging

## COLORECTAL CANCER SCREENING

- and Cox hazard analysis of mortality trends in a Mennonite community from south-central Kansas. *American Journal of Human Biology*, 18, 387-401.
- Moghaddam, A. A., Woodward, M., & Huxley, R. (2007). Obesity and risk of colorectal cancer: a meta-analysis of 31 studies with 70,000 events. *Cancer Epidemiology Biomarkers and Prevention*, 16(12), 2533-2547.
- Moss, R. W. (2005). Tijuana cancer clinics in the post-NAFTA era. *Integrative Cancer Therapies*, 4, 65-86.
- Nadel, M. R., Shapiro, J. A., Klabunde, C. N., Seeff, L. C., Uhler, R., Smith, R. A., et al. (2005). A national survey of primary care physicians' methods for screening for fecal occult blood. *Annals of Internal Medicine*, 142(2), 86-94. Retrieved December 18, 2009 from <http://www.annals.org/content/142/2/86.full.pdf+html>
- Ning, Y., Wang, L., & Giovannucci, E. L. (2009). A quantitative analysis of body mass index and colorectal cancer: findings from 56 observational studies. *Obesity Review*. doi: 10.1111/j.1467-789X.2009.00613.x
- National Cancer Institute (2008, March). State Cancer Profiles. Retrieved March 30, 2008 from <http://statecancerprofiles.cancer.gov/index.html>
- Old Order Mennonite Communities (2009). Unpublished community directory.
- Orton, N. C., Innes, A. M., Chudley, A. E., & Bech-Hansen, N. T. (2008). Unique disease heritage of the Dutch-German Mennonite population. *American Journal of Medical Genetics*, 146A, 1072-1087.
- Partin, M. R., Grill, J., Norrbaloochi, S., Powell, A. A., Burgess, D. J., Vernon, S. W., Halek, K., Griffin, J. M., van Ryn, M., & Fisher, D. A. (2009). Validation of self-reported colorectal Cancer screening behavior from a mixed-mode survey of

## COLORECTAL CANCER SCREENING

veterans. *Cancer Epidemiology Biomarkers & Prevention*, 17, 768-776.

doi:10.1158/1055-9965.EPI-07-0759.

Pignone, M. Russell, L. B. and Wagner, J. (eds.) (2005). Economic models of colorectal cancer screening in average risk adults. Retrieved from

[http://www.nap.edu/catalog.php?record\\_id=11228](http://www.nap.edu/catalog.php?record_id=11228)

Poynter, J. N., Haile, R. W., Siegmund, K. D., Campbell, P. T., Figueiredo, J. C.,

Limburg, P., et al. (2009). Associations between smoking, alcohol consumption, and colorectal cancer, overall and by tumor microsatellite instability status.

*Cancer Epidemiologic Biomarkers and Prevention*, 18(10), 2745-2750.

Rearick, E. (2003). Amish and health care. *Journal of Undergraduate Nursing*

*Scholarship*, 5, Retrieved November 25, 2007 from

<http://www.juns.nursing.arizona.edu/articles/Fall%202003/rearick.html>

Ries L., Melbert, D., Krapcho, M., Mariotto, A., Miller BA, Feuer EJ, et al., (2007).

SEER Cancer Statistics Review, 1975-2004, National Cancer Institute. Bethesda,

MD, [http://seer.cancer.gov/csr/1975\\_2004/](http://seer.cancer.gov/csr/1975_2004/)

Stokamer, C. L., Tenner, C. T., Chaudhuri, J., Vazquez, E., & Bini, E. J. (2005).

Randomized controlled trial of the impact of intensive patient education on

compliance with fecal occult blood testing. *Journal of General Internal*

*Medicine*, 20(3), 278-282, DOI: 10.1111/J.1525-1497.2005.40023.x

Suarez-Balcazar, Y., Harper, G. W., & Lewis, R. (2005). An interactive and contextual

model of community-university collaborations for research and action. *Health*

*Educations & Behavior*, 332, 84-101

Suh, E. E. (2004). The model of cultural competence through an evolutionary concept

## COLORECTAL CANCER SCREENING

- analysis. *Journal of Transcultural Nursing*, 15, 93-101.
- Terry, P., Giovannucci, E., Michels, K. B., Bergkvist, L., Hansen, H., Holmberg, L., et al. (2001). Fruit, vegetables, dietary fiber, and risk of colorectal cancer. *Journal of the National Cancer Institute*, 93(7), 525-533.
- Troyer, H. (1988). Review of cancer among 4 religious sects: Evidence that life-styles are distinctive sets of risk factors, *Social Science Medicine*, 26,1007-1017.
- U. S. Department of Health and Human Services (2009, August). Summary Health Statistics for U. S. Adults: National Health Interview Survey, 2008. Retrieved October 3, 2009 from [http://www.cdc.gov/nchs/data/series/sr\\_10/sr10\\_242.pdf](http://www.cdc.gov/nchs/data/series/sr_10/sr10_242.pdf)
- U.S. Preventive Services Task Force (July, 2002). Recommendations and Rational for Screening for Colorectal Cancer. Retrieved November 26, 2007 from <http://www.ahrq.gov/clinic/3rduspstf/colorectal/colorr.htm>
- Vernon, S. W., Meissner, H., Klabunde, C., Rimer, B. K., Ahnen, D. J., Bastani, R. & et al. (2004). Measures for ascertaining use of colorectal cancer screening in behavioral health services, and epidemiologic research. *Cancer Epidemiologic Biomarkers and Prevention*, 13, 898-905.
- Watson, J. (1988). New dimensions in human caring theory. *Nursing Science Quarterly*, 1, 175-181.
- Wells, M. I. (2000). Beyond cultural competence: A model for individual and institutional cultural development. *Journal of Community Health Nursing* 17, 189-199.
- Wenger, A. F. Z. (1995). Cultural context, health, and health care decision making. *Journal of Transcultural Nursing*, 7, 3-14.

## COLORECTAL CANCER SCREENING

- Wenger, L. (2003). *Unser satt leit: Our sort of people health understandings in the old order Mennonite and Amish community*. Unpublished master's thesis, University of Waterloo, Waterloo, Canada.
- Westman, J. A., Ferketich, A. K., Kauffman, R. M. MacEachern, S. N., Wilkins, J. R., Wilcox, P. P. & et al. (2009). Low cancer incidence rates in Ohio Amish. *Cancer Causes Control*, doi: 10.1007/s10552-009-9435-7
- Whitlock, E. P., Lin, J. S., Liles, E., Beil, T. L., & Fu, R. (2008). Screening for colorectal cancer: a targeted, updated systematic review for the U.S. Preventive Services Task Force. *Annals of Internal Medicine*, 149(9), 638-658.
- Wolin, K. Y., Yan, Y., Colditz, G. A., & Lee, I. M. (2009). Physical activity and colon cancer prevention: a meta-analysis. *British Journal of Cancer*, 100(4), 611-616.
- Young Center for Anabaptist and Pietist Studies, Elizabethtown College (2008). Amish population growth 1992-2008. Retrieved November 1, 2008 from highlights.[http://www2.etown.edu/amishstudies/Population\\_Trends\\_1992\\_2008.asp](http://www2.etown.edu/amishstudies/Population_Trends_1992_2008.asp).

# COLORECTAL CANCER SCREENING

## Appendix A

### Colorectal Cancer Screening Questionnaire

The following questions are about you, your health practices, your health history, and any colorectal cancer screening you may have received in the past.

1. Are you male or female?

male

female

2. What is your age? \_\_\_\_\_

3. What is your height? \_\_\_\_\_ feet \_\_\_\_\_ inches

4. What is your weight? \_\_\_\_\_ pounds

5. Do you smoke?  yes  no

6. Please indicate if you are

single

married

widow or widower

7. When was the last time you saw a health care provider for a check-up?

within the past 6 months

between 6 months and one year ago

between one year and two years ago

between two and five years ago

more than five years ago

never

don't know

8. Have you ever had colorectal cancer?

Colorectal cancer is a disease in which cells in the colon or rectum become abnormal and divide without control, forming a mass called a tumor.

Yes

No

Not sure/don't know

9. Have you ever had colon polyps?

A polyp is a growth of tissue that starts in the lining of the digestive system and grows into the center of the colon or rectum. Some polyps can become cancerous.

Yes

No

Not sure/don't know



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10. Have you ever been told you have Crohn's disease?  
Crohn's disease is a type of chronic inflammatory bowel disease. In this condition the small bowel and more rarely the colon is inflamed over a long period of time.  
Yes  
No  
Not sure/don't know
11. Have you ever been told you have Ulcerative Colitis?  
Ulcerative colitis is a type of inflammatory bowel disease in which the colon is inflamed over a long period of time.  
Yes  
No  
Not sure/don't know
12. Did either of your parents have colorectal cancer before the age of 60 years?  
Yes  
No  
Not sure/don't know
13. Do you have any brothers or sisters who have or have had colorectal cancer before the age of 60 years?  
Yes (if yes please indicate how many)  
No  
Not sure/don't know
14. Do you have any children who have or have had colorectal cancer?  
Yes (if yes please indicate how many)  
No  
Not sure/don't know
15. Has anyone in your family ever been diagnosed with familial adenomatous polyposis?  
Familial adenomatous polyposis is an inherited condition that is a risk factor for the development of colorectal cancer at a young age. Individuals with this syndrome typically develop hundreds of polyps in the colon and rectum.  
Yes  
No  
Not sure/don't know

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16. Has anyone in your family ever been diagnosed with hereditary non-polyposis colon cancer? Hereditary non-polyposis is an inherited condition that greatly increases a person's risk for developing colorectal cancer as well as endometrial cancer, ovarian cancer, small bowel cancer or cancer of the lining of the kidney. Individuals with this condition tend to develop cancer at a young age without first having many polyps.
- Yes
  - No
  - Not sure/don't know

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 three cards to determine whether the stool contains blood. You smear a sample of your fecal matter or stool on a card from three separate bowel movements and return the cards to be test.

17. Have you ever heard of a fecal occult or stool blood test?
- Yes
  - No
  - Not sure/don't know
18. Have you ever done a stool blood test using a "home" test kit?
- Yes
  - No
  - Not sure/don't know
19. If you answered yes to the previous question how many stool blood tests have you done in the last 5 years? \_\_\_\_\_
20. When did you do your most recent home stool blood test?
- A year ago or less
  - More than 1 year ago but not more than 2 years ago
  - More than 2 years ago but not more than 5 years ago
  - More than 5 years ago
  - Not sure or don't know
21. Why did you do your most recent home stool blood test?
- part of a routine examination or checkup
  - because of a symptom or health problem
  - follow-up from an earlier abnormal test
  - Not sure or don't know

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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.

22. With a sigmoidoscopy you are awake, you are able to drive yourself home, and you are able to resume your normal activities. Have you ever had a sigmoidoscopy?
- Yes
  - No
  - Not sure/don't know
23. If yes, when was your most recent sigmoidoscopy?
- A year ago or less
  - More than 1 year ago but not more than 5 years ago
  - More than 5 years ago but not more than 10 years ago
  - More than 10 years ago
  - Not sure/don't know
24. Why did you have your most recent sigmoidoscopy?
- part of a routine examination or checkup
  - Because of a symptom or health problem
  - Follow-up from an earlier abnormal test
  - Not sure or don't know
25. With a colonoscopy, you are given medicine through a needle in your arm to make you sleepy, you need someone to drive you home, and you may need to take the rest of the day off from your usual activities. Have you had a colonoscopy?
- Yes
  - No
  - Not sure/don't know
26. If yes, when was your most recent colonoscopy?
- A year ago or less
  - More than 1 year ago but not more than 5 years ago
  - More than 5 years ago but not more than 10 years ago
  - More than 10 years ago
  - Not sure/don't know
27. Why did you have your most recent colonoscopy?
- part of a routine examination or checkup
  - Because of a symptom or health problem
  - Follow-up from an earlier abnormal test
  - Not sure or don't know

# COLORECTAL CANCER SCREENING

## Appendix B

### Educational Offering

The education will consist of the content from the “Screen for Life Facts on CRC Screening Brochure.” In a group format, a flip chart will be used to display diagrams of the colon, physical conditions that are high risk for colorectal cancer, types of colorectal cancer screening tests, and symptoms of colorectal cancer. A brochure will be given to each participant. The presentation will be made by the investigator and questions will be encouraged. The length of the presentation with questions is about 30 minutes.

### Content

#### What is Colorectal Cancer?

Colorectal cancer is cancer that occurs in the colon or rectum. Sometimes it is called colon cancer, for short. As the drawing shows, the colon is the large intestine or large bowel. The rectum is the passageway that connects the colon to the anus.

#### It’s the Second Leading Cancer Killer

Colorectal cancer is the second leading cancer killer in the United States, but it doesn’t have to be. If everybody age 50 or older had regular screening tests, at least one-third of deaths from this cancer could be avoided. So if you are 50 or older, start screening now.

#### Who Gets Colorectal Cancer?

- Both men and women can get colorectal cancer.
- Colorectal cancer is most often found in people 50 and older.
- The risk for getting colorectal cancer increases with age.

#### Are You at High Risk?

Your risk for colorectal cancer may be higher than average if:

- You or a close relative have had colorectal polyps or colorectal cancer.
- You have inflammatory bowel disease.

People at high risk for colorectal cancer may need earlier or more frequent tests than other people. Patients with at high risk should receive a colonoscopy.

#### Screening Saves Lives

If you’re 50 or older, getting a screening test for colorectal cancer could save your life. Here’s how:

- Colorectal cancer usually starts from polyps in the colon or rectum. A polyp is a growth that shouldn’t be there.
- Over time, some polyps can turn into cancer.
- Screening tests can find polyps, so they can be removed *before* they turn into cancer.
- Screening tests can also find colorectal cancer early. When it is found early, the chance of being cured is good.

#### Colorectal Cancer Can Start With No Symptoms

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People who have polyps or colorectal cancer sometimes don't have symptoms, especially at first. This means that someone could have polyps or colorectal cancer and not know it. That is why having a screening test is so important.

### What are the Symptoms?

Some people with colorectal polyps or colorectal cancer do have symptoms. They may include:

- Blood in or on your stool (bowel movement).
- Pain, aches, or cramps in your stomach that happen a lot and you don't know why.
- A change in bowel habits, such as having stools that are narrower than usual.
- Losing weight and you don't know why.

If you have any of these symptoms you need to see a health care provider. These symptoms may also be caused by something other than cancer. However, the only way to know what is causing them is to see your health care provider.

### Types of Screening Tests

There are several different screening tests that can be used to find polyps or colorectal cancer. Each one can be used alone. Sometimes they are used in combination with each other. Talk to your doctor about which test or tests are right for you and how often you should be tested.

#### • Fecal Occult Blood Test or Stool Test

For this test, you receive a test kit from your doctor or health care provider. At home, you put a small piece of stool on a test card. You do this for three bowel movements in a row. Then you return the test cards to the doctor or a lab. The stool samples are checked for blood. How Often: This test should be done every year.

#### • Flexible Sigmoidoscopy

For this test, the doctor puts a short, thin, flexible, lighted tube into your rectum. The doctor checks for polyps or cancer inside the rectum and lower third of the colon. How Often: This test should be done every 5 years.

#### • Fecal Occult Blood Test Plus Flexible Sigmoidoscopy

Your doctor may ask you to have both tests. Some experts believe that by using both tests, there is a better chance of finding polyps or colorectal cancer.

#### • Colonoscopy

This test is similar to flexible sigmoidoscopy, except the doctor uses a longer, thin, flexible, lighted tube to check for polyps or cancer inside the rectum and the entire colon. During the test, the doctor can find and remove most polyps and some cancers.

How Often: This test should be done every 10 years.

Colonoscopy may also be used as a follow-up test if anything unusual is found during one of the other screening tests.

#### • Double Contrast Barium Enema

This test is an x-ray of your colon. You are given an enema with a liquid called barium. Then the doctor takes an x-ray. The barium makes it easy for the doctor to see the outline of your colon on

the x-ray to check for polyps or other abnormalities. How Often: This test should be done every 5 years.

Content adapted from Screen for Life: Colorectal Cancer: Basic Facts on Screening. Retrieved December 31, 2008 from <http://www.cdc.gov/cancer/colorectal/pdf/fs-patient-basic.pdf>  
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Appendix D

Patient Notification Letter Positive

Dear Community Member,

This letter is to let you know that your fecal occult blood test was positive. We recommend that you follow-up with your health care provider. The recommendation of the American Cancer Society following a positive fecal occult blood test is that you have a colonoscopy.

I will be visiting the community on \_\_\_\_\_ from \_\_\_ to \_\_\_ if you have any further questions.

Eve Main MSN, FNP-BC

Appendix E

Patient Notification Letter Negative

Dear Participant,

This letter is to let you know that your fecal occult blood test was negative. The recommendation of the American Cancer Society is that you repeat the fecal occult blood test yearly. Yearly fecal occult blood testing has been shown to reduce the deaths from colorectal cancer.

I will be visiting the community on \_\_\_\_\_ from \_\_\_\_ to \_\_\_\_ if you have any further questions.

Eve Main MSN, FNP-BC



## Appendix F

## Hemoccult Sensa Instructions

You should follow the instructions below before and during your stool collection period.

1. Some substances interfere with fecal occult blood tests. For the most accurate test results you should do the following:  
Avoid non-steroid anti-inflammatory drugs such as ibuprofen, naproxen, or motrin for seven days before and during the stool collection.  
Avoid vitamin C supplements and citrus fruits and juices for 3 days before and during the stool collection.  
Avoid red meats (beef, lamb, and liver) for 3 days before and during the stool collection.

The Hemoccult II Sensa slides are designed so that patients can collect stool specimens at home from bowel movements over three days. The stool samples should be taken at least one day apart and should be applied to each test card from three different days.

2. Do not collect samples if blood is visible in your stool or urine such as with menstruation, active hemorrhoids, or urinary tract infection.
3. Use a ball-point pen to write your name and date of collection on the front of each slide.
4. Use a dry clean container to collect your sample.
5. Using the stick provided apply a thin smear to box a on slide 1, then collect a second sample from a different part of the stool with the same stick and apply to box b.
6. Close and secure front flap of section 1. Store slide in any paper envelope until the next day and protect the slides from heat, light, and chemicals.
7. Repeat steps 4 through 7 until you have collected three stool samples.
8. After completing each slide, return the kit within 14 days in the provided mailer.

Hemoccult Fecal Occult Blood Tests Web site. Patient Instructions Retrieved February 1, 2009 from [http://www.hemoccultfobt.com/patients/patients\\_HemoII\\_Sensa\\_Pt\\_Instr.htm](http://www.hemoccultfobt.com/patients/patients_HemoII_Sensa_Pt_Instr.htm)