

Colorectal Cancer Awareness and Risk Education

TELECARE Intervention Manual



Study Overview

The Family Care Project is a research study that aims to develop an exportable telephone-based cancer risk counseling intervention to promote risk-appropriate colorectal (CRC) screening. The target population were individuals at increased familial risk for CRC who reside in geographically underserved areas with regard to access to specialized clinical cancer risk assessment and counseling services. This 2-group randomized trial compared a group that received a telephone-delivered, theory-based remote tailored cancer risk assessment and behavior change counseling intervention (TELECARE) delivered by trained cancer risk counselors, with a group who received a mailed pamphlet about familial colorectal cancer risk and screening. Seven-hundred and twelve men and women at increased risk of familial CRC who resided in rural or remote areas in Idaho and Utah were randomized to one of the two study groups after they completed a mailed or telephone baseline survey. The TELECARE telephone sessions lasted approximately 45 minutes. The primary aim was to determine if a high intensity tailored risk communication intervention (TELECARE) was superior to a low intensity targeted intervention in promoting colonoscopy. Secondary aims were to compare the two study groups with regard to cognitive and emotional outcomes and explore the underlying mechanisms through which the interventions had an impact on CRC screening.

Individuals randomized to the intervention group received a tailored cancer risk assessment and behavior change counseling session conducted by board-certified genetic counselors trained in behavioral theory and brief motivational interviewing who:

- 1) Established rapport and discussed familial experience with CRC.
- 2) Discussed experience with colonoscopy and other types of CRC screening.
- 2) Discussed general thoughts and feelings about colorectal cancer and colonoscopy.
- 3) Assessed concerns and worries about CRC and colonoscopy and counseled accordingly.
- 4) Addressed select theory-based constructs (i.e., perceived threat and efficacy, stage of readiness, provider communication, barriers, cues to action, and social norms) to increase motivation to get screened for CRC and helped participants make a plan to do so.
- 5) Encouraged participants to talk with their health care provider (and secure a primary care provider if they do not have one) about their family history and the recommendations for colonoscopy.
- 6) Incorporated motivational interviewing (MI) principles (such as how to deal with resistant and ambivalent participants) to be used when appropriate.
- 7) Guided participants in developing an action plan.
- 8) Answered participants' questions.

Following the TELECARE session, participants received a tailored follow-up letter summarizing key points of the session (i.e., increased familial colorectal cancer risk, colonoscopy recommendation and FOBT as an option for those who identify lack of health insurance or identify cost as a barrier, importance of provider communication about their CRC risk and risk-appropriate screening, messages about response efficacy and ways to overcome their two most important barriers), a copy of their cancer-related pedigree, and an action plan postcard. With their permission, a cover letter and a copy of the tailored letter summarizing key points of the session was sent to their primary care provider. Follow-up questionnaires were sent to participants at 1 month and 9 months, and for those who reported that they had not had

a colonoscopy, an additional questionnaire at 15 months. The primary outcome was colonoscopy screening. An easier and less expensive way to get tested for colorectal cancer, FOBT screening, was considered as a secondary outcome.

Theoretical Background & Rationale

Theory-based interventions addressing multiple determinants of behavior have the highest likelihood of promoting healthy behaviors (Briss et al., 2004). TELECARE explicitly incorporates health communication and behavioral theories as well as motivational interviewing principles into the design and implementation of the intervention. Given the complexity of the relationships between risk communication, informed decision making, and health behavior, it is often necessary to judiciously combine constructs from several theories or models that have been validated in prior research (Briss et al., 2004; Irwig et al., 2006). Our telephone-based, tailored risk communication intervention integrates several behavior change theories and conceptual models: Health Belief Model (HBM; Janz & Becker, 1984; Rosenstock, 1966), Transtheoretical Model (TTM; DiClemente & Prochaska, 1982), and Extended Parallel Process Model (EPPM; Witte, 1992). These theories provide a framework for incorporating both cognitive and emotional factors into the intervention and motivating behavior change. Specifically, the HBM posits that individuals will adopt the desired health behavior (i.e., having colonoscopy) if they perceive the threat of disease (CRC) to be high (perceived susceptibility), perceive the consequences to be severe (perceived severity), and perceive more benefits of getting screened than barriers. The HBM also considers cues to action (e.g., reminders and social influence) and self-efficacy (confidence in one's ability to obtain a colonoscopy), as well as the importance of other factors (e.g., knowledge, sociodemographics, social support, and other access factors).

The TTM was selected to assess stage of readiness to have a colonoscopy, and guide the use of appropriate motivational counseling techniques according to an individual's stage of change (e.g., dealing with ambivalence for contemplators). The model postulates that tailored interventions that address stage of readiness will be more successful in motivating colonoscopy. There is considerable empirical evidence indicating that the probability of behavior change is directly related to perceptions of the "pros" (benefits) of the target behavior, and inversely related to the "cons" (perceived barriers) of the target behavior, and is often referred to as the strong-weak principle of behavior change. Both HBM and TTM consider this principle (Rosenstock, 1966; DiClemente & Prochaska, 1982). TELECARE will use TTM to assess participant's stage of readiness to have colonoscopy. TTM stages are shown in Table 1. The stage of each participant determines, in part, the communication they will receive during the intervention. For instance, those who are unaware of colonoscopy would receive more information about the procedure while those who are contemplators would receive less education about colonoscopy and more time would be devoted to assisting participants make a decision using motivational interviewing principles that consider participants' weighing of the pros and cons of colonoscopy.

Table 1. Stage of readiness according to TTM

Stage	Peoples' readiness to change	
Unaware	Do not know about colorectal cancer and/or colonoscopy	
Precontemplation	Unmotivated or under-informed about colonoscopy	
Contemplation	Gathering information and considering having a colonoscopy	
Preparation	Planning to have a colonoscopy soon	
Action	Already scheduled for a colonoscopy	
Maintenance	Continuing to have colonoscopies	
Relapse	Have had a colonoscopy in the past, but are not thinking about having one again.	
Note: People who are in either the preparation, action, or maintenance stages		

are not eligible for participation in the study

Because neither the HBM nor TTM emphasizes the role of affect, we chose to incorporate the EPPM to account for the role of emotions in the delivery of and responses to risk communications. The EPPM focuses on how to channel fear in a positive protective direction instead of a negative maladaptive direction. The EPPM incorporates perceived threat (perceived susceptibly and severity) and efficacy from the HBM and adds a fear response. According to this model, when a person is presented with a fear appeal (e.g. in the form of a risk appraisal or assessment) depicting the components of threat (i.e. disease susceptibility and severity), the response may result in high or low perceived threat. When the threat is perceived as high, fear is elicited and people are motivated to begin the second appraisals, which are the evaluations of the efficacy of the recommended action and ability of oneself to execute it. If the threat is perceived as low, then there is no motivation to process the message further, efficacy is not evaluated by the participant, and there is no response to the fear appeal (e.g. do not intend to have a colonoscopy).

EPPM posits that increased susceptibility and severity leads to fear of disease (CRC) and its outcomes. Fear will motivate people to consider possible solution(s) to prevent the threat of cancer (colonoscopy). According to the model, individuals who believe that the recommended behavior is effective in preventing or reducing their risk of the threat (response efficacy) and have confidence in their ability (self-efficacy) to execute the behavior (e.g., can overcome existing barriers) will adaptively perform the recommended behavior in an attempt to control the danger. In contrast, individuals who feel fearful and threatened but do not believe that the recommended behavior will help prevent the threat and/or have low self-efficacy will try to control their fear (e.g., through defensive avoidance) instead of controlling the threat itself. EPPM prescribes that people should first be aware of their increased risk and then presented with a recommended behavior. The structure of the intervention is determined by the EPPM as shown in Figure 1. The genetic counselors will start by addressing participants' increased risk for colorectal cancer and how serious the disease is in order to heighten perception of threat. After participants are made aware of the threat (or threat is reinforced), the counselors will discuss how participants can prevent CRC or reduce their risk of dying from the disease by

addressing the effectiveness of colonoscopy and their confidence in having one. Barriers counseling is an important way to enhance participant's self-efficacy regarding colonoscopy utilization.

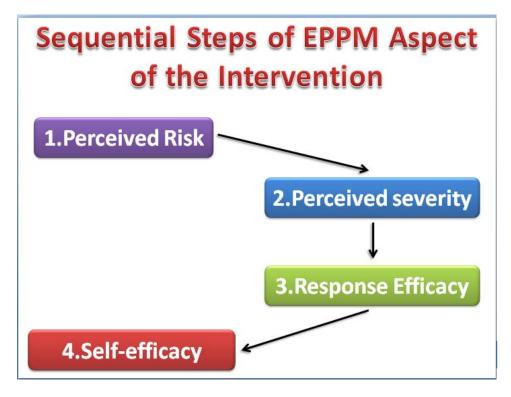


Figure 1. Steps of the intervention according to the EPPM

In terms of the delivery style, the intervention will use elements of motivational interviewing (MI), an evidence-based communication strategy. MI is a participant-centered, directive style of interacting with a person to help explore and resolve ambivalence about change (Miller & Rollnick, 2002). MI borrows from Participant-Centered Counseling in its emphasis on empathy, optimism, and respect for participant choice (Rogers, 1961). MI also draws from Self-Perception Theory, which asserts that a person becomes more or less committed to an action based on the verbal stance he or she takes (Bem, 1972). Thus, a person who talks about the benefits of change is more likely to make that change, whereas a person who argues and defends the status quo is more likely to continue in the present behavior. Finally, MI is also logically connected to the TTM model, which says that people go through a sequence of stages when thinking about change (Prochaska & Velider, 1997). Research suggests that MI is particularly useful for those participants who are less ready for change.

Because MI is a communication style, rather than a set of techniques, it is usually introduced in terms of a set of stylistic principles: (1) Express Empathy, which involves a respectful, curious attitude; (2) Roll with Resistance, which emphasizes avoiding arguments whenever possible and finding other ways to respond when challenged; (3) Develop Discrepancy, which means that the provider works to elicit the person's own reasons for change; and (4) Support Self-Efficacy, which emphasizes positive language and an environment that is supportive of change.

The Ottawa Decision Support Framework (ODSF) is also used in our study to examine the role of cognitive factors, such as knowledge about the disease and recommended behavior and decisional conflict. The intervention will provide participants with knowledge about CRC and colonoscopy as well as help them in making an informed decision about getting screened that is consistent with their values.

Below is a schematic of our study model (Figure 2) that integrates important theoretical constructs which are hypothesized to motivate colonoscopy use.

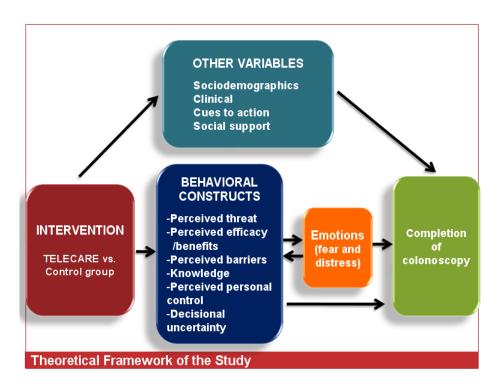


Figure 2. Theoretical framework of the study

Consistent with the study model, the genetic counselors will need the following data from each participant in order to intervene on the targeted constructs (intervention targets):

- 1. Personal medical and family history
- 2. Perceptions of threat and efficacy
- 3. Baseline survey responses to select items: barriers, benefits, decisional uncertainty (decision to get or not to get screened), colorectal cancer and screening knowledge, self-reported health status, presence of a primary care provider, provider communication, information about the last time they had a routine health check-up, and family communication about their colorectal cancer risk and colonoscopy screening.

Available data suggests that thinking about future behavior in relation to specific environmental cues of when, where, and how to enact a particular behavior increases the frequency of or enactment of that behavior. There is evidence showing that when threatening health messages (e.g., risk communications and fear appeals) are combined with action (implementation plans), the likelihood of the behavior occurring increases (Schweiger & Gollwitzer, 2007). Prior research indicates that action-oriented plans, also known as

implementation-intention strategies, that emphasize the action required to meet the goal increases the chances of successfully reaching an intended future goal (i.e., getting a colonoscopy) with minimal effort by making conscious, deliberate behaviors automatic (Gollwitzer & Sheeran, 2006; Sheeran& Orbell, 2000; Sheeran & Silverman, 2003). Implementation-intention strategies have the structure: "When situation *x* arises, I will perform response *y*"; the situation is specified in terms of time and place. Participants typically are asked to make their own plan of "when and where" they will implement a given behavior.

During the TELECARE session, counselors will follow an intervention protocol in discussing participants' increased risk for colorectal cancer and colonoscopy as a recommended behavior. The following sections also describe strategies that counselors will use while communicating with participants. Health messages will be personalized with regard to the participant's objective CRC risk as well as the study's aforementioned key theoretical constructs: state of change/readiness, perceived threat (susceptibility and severity), perceived efficacy (response and self-efficacy), health care factors (routine check-up behavior, presence of a primary care provider), social influence (communication with provider about familial risk and colonoscopy recommendation and family communication), and cues to action (action plan and action plan reminder). Before the session starts, the counselors will have a document folder containing each participant's information gathered from the baseline questionnaire and also the Risk Behavior Diagnosis Scale RBD scores ready. The RBD scores will give counselors an overall idea of what main construct(s) they should focus on in their discussion with each participant.

1. GREETING AND INTRODUCTION

Purpose:

- Orient the participant to the structure of the phone call by providing a basic summary of the interaction.
- Orient the participant to the style of the interaction, through a warm, friendly attitude.

Steps:

- 1. Prior to calling, review the Participant Synopsis form (see Appendix A).
- 2. Introduce yourself and remind the participant about the Family CARE Project.
- 3. Ascertain that the participant has the desired level of privacy in their location and there is no distraction during the session.
- 4. Inform the participant that the phone conversation is being recorded for quality control purposes, but that they can refuse recording or stop the conversation at any time.
- 5. Remind the participant that all information is confidential.
- 6. Ask the participant if they have the sealed envelope that was mailed to them for the TELECARE session. Give them a moment to locate it if necessary. If they do not have it at the time of the session, check if the participant is able to receive the visual aid file via email or fax, try to fax or email the visual aid file. If they cannot locate the envelope or have the information sent to them electronically then cancel the session, ask an FCARE staff to resend the envelope, and reschedule the session. If the participant also indicates that they do not have 45 minutes or it seems like they may be too distracted, the session

should also be rescheduled. If the session gets interrupted in the middle, ask the participant if it is still a good time to continue the session. If the session has to be stopped in the middle, it should be rescheduled as soon as possible.

- 7. Elicit participant's thoughts about the purposes of the session and lay out the basic structure of the session.
 - The conversation will last about 45 minutes.
 - Basic goal is to determine where they are in their thinking about getting a colonoscopy, and to provide information so they can make the choice that is right for them.

Visual aids

Several visual aids will be used to help participants in following the discussion with counselors regarding their increased risk and other theoretical constructs. These visual aids will be tailored for each participant according to his/her responses on the baseline questionnaire. For example, for a single item measure of perceived relative risk, a participant will received visual aids saying "You think your risk of colorectal cancer is lower than the average person" or "Your important barriers are that you don't have transportation to get a colonoscopy and that the cost of a colonoscopy is too high." Specifically, there will be four visual aids that will be sent to participants to be used during the session. They are:

- 1. Family tree
- 2. Risk perception
- 3. Survival rates according to the stage of cancer when diagnosed
- 4. Important barriers and action plan table

2. REVIEW MEDICAL AND FAMILY HISTORY

After the introduction, counselors move to a discussion with participants about their basic medical information and family history data obtained from the baseline questionnaire.

Purpose:

- Verify family history of colorectal cancer
- Determine the participants' experience with colon or rectal cancer (e.g., family history, caregiving role) using the baseline survey information regarding family history, followed by additional questions.

Strategies:

Introduction: Ex. "What I'd like to do now is to review some of the family history information you provided and ask you some additional questions about your experiences. This will help me to be able to give you information that is tailored to your specific situation. I want to stress again that all of this is designed to be helpful for you, but please let me know if you have any concerns about anything we are talking about."

• After reviewing the participant's family history for accuracy (refer to the pedigree in the visual aid pack), the counselor will explore the following:

- Experience with family members' colon or rectal cancer (determine role)
 - Primary caregiver
 - Provided some care/support
 - Contact with the family member, but no direct care
 - No contact with affected family member during treatment
- Encourage participants to tell more about how their family members' cancer was diagnosed and how the experience affects them
 - During routine screening
 - Relative had screening, but developed interval cancer
 - Relative was not screened, and cancer was detected due to symptoms
 - No information
- Communication within the family about risk and colorectal cancer screening
 - If family member has discussed risk, follow-up on what was discussed, who the participant has talked with, and whether other relatives are pursuing screening (i.e., with colonoscopy or other risk-inappropriate screenings).
 - If no family discussion, assess how family members discuss other types of medical issues and the role of family in making medical decisions.
- Counselors reflect and affirm difficult experience of having colorectal cancer

3. IDENTIFY PARTICIPANTS' PERCEPTIONS OF THREAT AND EFFICACY

This section begins with describing how to use the Risk Behavior Diagnosis (RBD) scale scores (for counselor) and then how to address each EPPM key construct as specified by the model.

<u>Purpose:</u> This step provides information about the participants' level of perceived threat (i.e., colorectal cancer) and their perception of efficacy to overcome it.

According to EPPM, these two types of beliefs are identified by participants' scores on the RBD.

Perceived threat is comprised of two cognitive factors:

- Perceived susceptibility (perceived risk)
- Perceived severity

Efficacy is also operationalized as two cognitive factors:

- Response efficacy
- Self-efficacy

Strategies:

- 1. Use participants' RBD scores to get an overall idea of what participants are thinking in terms of the threat and efficacies.
- 2. Use motivational interview techniques by focusing on the lower scored areas. Counselors can do this by:
 - 1) Asking participants about the reasons why he or she believes that cancer is threatening or how they can overcome the threat (i.e., why they did not score *lower* in a particular area), and;
 - 2) Providing information to raise the participants' perception of threat or efficacy.
 - 3) Strategically using the "importance of/confidence in getting a colonoscopy" rulers (see Section 4) to help identify screening readiness.

Participants' scores from the RBD scale will be used to determine what constructs should be emphasized in increasing motivation and ability to get a colonoscopy. Figure 3 provides an example of an individual's RBD score. All four constructs should be addressed with ALL participants in the following order: perceived susceptibility, perceived severity, perceived response efficacy, and perceived self-efficacy.

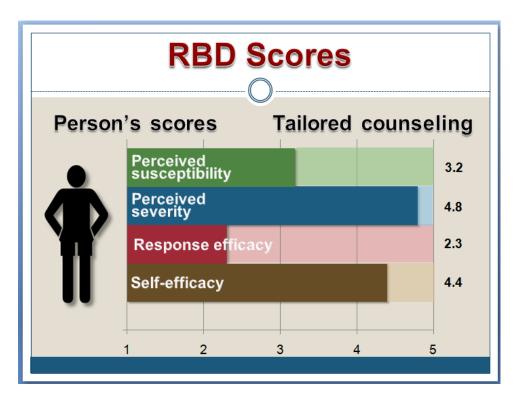


Figure 3. Example of a participant's RBD scores

<u>Step 1: A quick glance.</u> (For each participant, a graph similar to Figure 3 should be ready on the counselors' computer screen and/or printed to be used at the beginning of the session to be used throughout the whole counseling session). First, examine the participant's combination of scores on the 4 EPPM constructs. Scores are categorized as high, moderate, or low (See Figure 4 for categorization criteria). The purpose of this step is for the counselors to get a rough idea of what construct(s) they should emphasize in the intervention. In this example, the participant scored lowest on "Response efficacy." Therefore, greater effort should be put into

increasing the participant's perceived risk and beliefs about the effectiveness of having a colonoscopy.

<u>Step 2: Provide tailored messages.</u> Counselors address each EPPM construct beginning with perceived susceptibility. For example, this participant (Figure 3) will receive a tailored message for moderate perception of risk. He/She will be given more information about his/her personal risk due to genetic link (and some other risk factors if applicable) in order to increase their risk perception. Then, since this person is already aware of the danger of the cancer, a tailored message for high perception of severity will be provided and a

Figure 4. Criteria used to categorize participants according to their RBD scores (average score on each construct ranges from 1 to 5).

- Low = 1-2.0
- Moderate = 2.1-3.5
- High = 3.6-5

counselor should spend a short time intervening on this belief. However, the counselor will need to correct the participant's belief about the effectiveness and necessity of colonoscopy since the person has the lowest score on this construct. Finally, the counselor will spend a brief amount of time discussing barriers to screening and the person's confidence about getting screened since this person seems ready to have one if he/she wants to.

Figure 5 provides an additional example of how to use RBD scores in personalizing the counseling session.

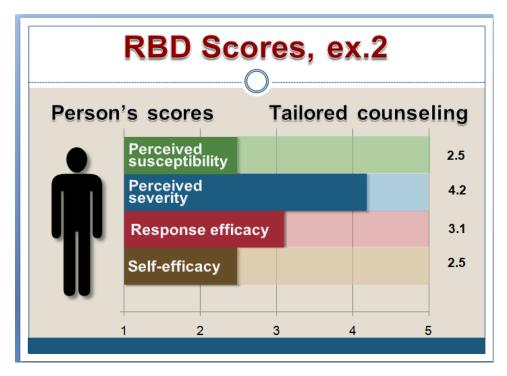


Figure 5. Another example of a participant's RBD scores

<u>Step 1: A quick glance.</u> For this example (Figure 5), the participant has moderate to low perceived risk, high perceived severity, moderate response efficacy, and relatively low self-efficacy. In other words, this person thinks he/she is not at increased risk for colorectal cancer but he/she is aware that cancer is dangerous. Although having a colonoscopy seems to be effective in preventing the cancer, the participant believes that it is too difficult to do so. Therefore, the counselor should put greater effort into discussing the participant's increased risk

for colorectal cancer and the effectiveness of colonoscopy, as well as in helping this person overcome important barriers to getting screened. In general, persons with low self-efficacy have more salient barriers.

<u>Step 2: Provide tailored messages.</u> This participant will be given tailored messages regarding his/her personal risk due to their genetic link in order to increase risk perception. Then, since the participant is already aware of the seriousness of colorectal cancer, the counselor will affirm this belief. Since this participant is not certain about the effectiveness and necessity of having a colonoscopy, the counselor will provide more information about these issues. Finally, it is very important that the counselor helps this participant overcome barriers to screening so that he/she is more confident in their ability to adhere to the colonoscopy recommendation. The counselor will guide the participant in creating an action plan to schedule a colonoscopy within the next several weeks.

In this critical theoretical aspect of the intervention, tailored messages will be provided to participants according to their RBD scores and the stage of change.

Perceived susceptibility

<u>Purpose:</u> Ascertain that participants are aware of their increased risk. Counselors will need to give a tailored report about the influence of the participants' family history on their personal CRC risk.

Strategies:

- Counselors use participants' perceived susceptibility score from the RBD scale and their answer to questions from the baseline about relative risk (Do you think your chance of developing colorectal cancer is higher/lower/about the same compared to the average woman/man your age?")
- Present tailored risk information based on the participant's risk perceptions (Figure 6; visual aid page 2).
 - 1. Summarize the participant's risk assessment.
 - Ex. "The next section of the call focuses on your risk for developing cancer.
 On the survey, you estimated that your risk for colorectal cancer was (greater
 than, about the same, less than) the risk for other people of your age and
 gender.
 - 2. Refer to the survey slide and ask the person about their reaction to the risk comparison chart.
 - Ex. "On the visual aid, it shows your actual risk based on the information you provided. I'm wondering what you make of that."
 - "What do you think about your risk for colon cancer?"
 - "What concerns you about it?"
 - "How does that strike you?"

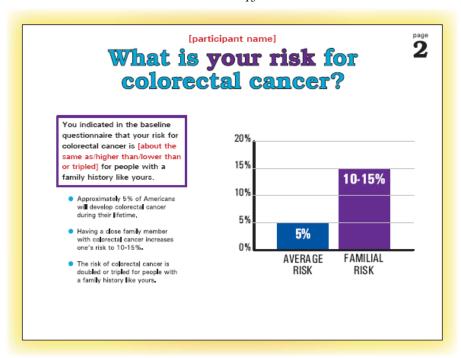


Figure 6. Visual aid: Personal risk estimation

3. Clarify and add information as appropriate (but the person's reaction is still most important).

A. Accurate risk:

Confirm individual's beliefs and emphasize the role of family history. Ex. "You indicated in the survey that you think your risk is higher than other people. What make you think that? ... You are right that you think your risk for colorectal cancer is higher than other people your age. And it's because of your family history that you have [insert personal information about relative(s) diagnosed with colorectal cancer]. Family history is one of the most important risk factors for colorectal cancer. Having [insert personal information about relative(s) diagnosed with colorectal cancer]. People with a family history like yours [tailor according to participant's family history] have double or triple of the risk comparing to those without family history of the cancer (explain the role of genetic factor).

B. Underestimated risk:

Explore the reasons of belief in low risk, provide more information regarding the influence of family history and elicit participant's response. Ex. "You may feel that your risk for colorectal cancer is lower than some of your family members or of other people your age because you have a healthier life style or are not that similar to your relative(s) who was diagnosed with colorectal cancer. However, family history is one of the most important risk factors for colorectal cancer. People who have a family history like yours have increased risk for colorectal cancer, double or triple of the risk of those without family history of the cancer (explain the role of genetic factor).

C. Overestimated risk:

 Explore the reason of belief in high risk, affirm, and present prevention information. Ex. "You are correct that your risk for colorectal cancer is high. However, from the information I have, let me make clear that it's not too high to lose hope in preventing it, and we are here to help you reduce your risk for colorectal cancer. What do you think? Do you think your risk can be reduced?"

Perceived severity

<u>Purpose:</u> To elicit and provide information about the seriousness of colorectal cancer. Counselors will need to provide statistical information about death rate as well as more qualitative information. EPPM studies indicate that statistical information is useful for fear appeals for some people.

Strategies:

- Reflect and provide more information about the severity of colorectal cancer
- Counselors may discuss the physical effects of advanced disease, treatment and morbidity, and cost of treatment with participants who have low perceived severity.

A. Low perceived severity

- Reflect and explore reasons
 - Ex. "So you're not really sure whether colorectal cancer is that serious."
- Provide information about severity
 - Ex. "There may be other things that are more on your mind. Just so you're aware, colorectal cancer is now the second leading type of cancer in the United States. That means that more than 50,000 people in the United States die from colorectal cancer every year. It can also cause a lot of pain and suffering. We want to make sure that people know about the risks of colorectal cancer, so they can make a decision that is right for them and their families."
- Encourage participants to think about negative consequences of having colorectal cancer
 - Ex. "What do you think about this? What would happen to you if you get colon cancer? What are some of your fears about having colon cancer?"

B. Moderate perceived severity

- Reflect and explore reasons
 - Ex. "So, you think that colorectal cancer is somewhat serious. What are some reasons you think it could be serious?"
- Summarize the person's reaction, provide additional information
 - Ex. "So the reasons you think it could be serious are... You're probably already aware that colorectal cancer is now the second leading type of cancer in the United States. That means that more than 50,000 people in the United States die from colorectal cancer every year. We want to make sure that people know about the risks of colorectal cancer, so they can make a decision that is right for them and their families.
- Encourage participants to think about negative consequences of having colorectal cancer
 - Ex. "What do you think about this? What would happen to you if you get colon cancer? What are some of your fears about having colon cancer?"

C. <u>High perceived severity</u>

Reflect, affirm, and provide the statistical information

- Ex. "So, you think that colorectal cancer is a serious disease. You are right. You're probably already aware that colorectal cancer is now the second leading type of cancer in the United States. That means that more than 50,000 people in the United States die from colorectal cancer every year. We want to make sure that people know about the risks of colorectal cancer, so they can make a decision that is right for them and their families.
- Present 5-year survival rates by stages (e.g., 92% survive if colorectal cancer is detected early; Figure 7, visual aid page 3).

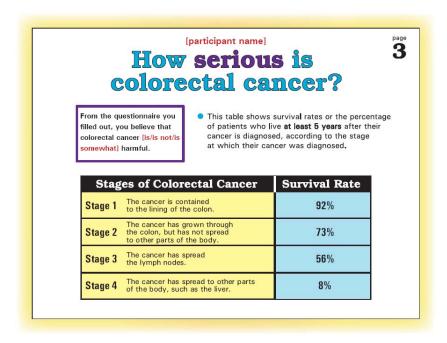


Figure 7. Visual aid: Colorectal cancer severity

- Ex. "The good news is that the severity of colon cancer depends on when it is detected. The survival rate is much higher if it is detected earlier. There's a little chart on page 3 of the visual aids—How serious is colon cancer?—that shows the survival rate by stage of cancer. It shows that... Moreover, colorectal cancer that is detected early can be treated in a much less aggressive way, for example, less likely to need chemotherapy, less likely to need colectomy. What do you think about that?"
- Introduce colonoscopy as one way to reduce risk of developing colon cancer.
 - Ex: "When we talk about ways to reduce risk, one thing we usually talk about is colonoscopy. There are several screening tests to check for colon cancer, but colonoscopy is the most comprehensive one and the one recommended for people with your family history."
- Elicit information about what the participant already knows about colorectal screening (Ex. What do you know about colonoscopy?). Add information as appropriate.

Response efficacy

<u>Purpose:</u> Participants believe that colonoscopy is the best way to prevent and detect colorectal cancer.

Strategies:

- Counselors elicit what participants already know about CRC screening, and their current screening status.
 - Ex. "What do you know about colorectal cancer screening?"
 - "What do you know about colonoscopy?"
 - "What are your plans to get a colonoscopy in the next 6 months?"
- Counselors provide information about colonoscopy, how it works, and its
 effectiveness in preventing and detecting colorectal cancer based on what
 participants know about it.
- Check if participants understand the procedure of having a colonoscopy.
- Recommend or reinforce getting a colonoscopy at the frequency based on each participant's family history

A. Low perceived response efficacy

- Reflect and ask the reason for their belief
 - Ex. "Prior to our discussion today, you indicated that you thought colonoscopies were not very effective in preventing colorectal cancer. What are some of the concerns you have about the test?"
- Then, reflect and provide more information
 - Ex. "So your main concern is... Actually, colonoscopy is very effective in both preventing and detecting colon cancer because it allows the doctor to check your entire colon in great detail for polyps or growths that may develop into cancer. Removing these polyps can prevent colorectal cancer from developing. As we discussed earlier, when colorectal cancer is detected and treated early, 92% of cases are cured. There are many types of colorectal cancer screening tests, but cancer specialists, such as the American Cancer Society and doctors at Huntsman Cancer Institute, recommend colonoscopy as the best way to screen for colon cancer for people with a family history. They also recommend that people with a family history like yours should begin having colonoscopy by age 40 (or 10 years earlier) and to have colonoscopies every 3-5 years".

B. Moderate perceived response efficacy

- Reflect and ask the reason for their belief
 - Ex. "Prior to our discussion today, you indicated that you thought colonoscopies were somewhat effective in preventing colorectal cancer. What are some of the reasons you think it's rather effective?"
- Then, reflect and provide more information
 - Ex. "So your reasons are... Actually, colonoscopy is very effective in both preventing and detecting colon cancer because it allows the doctor to check your entire colon in great detail for polyps or growths that may develop into cancer. Removing these polyps can prevent colorectal cancer from developing. As we discussed earlier, when colorectal cancer is detected and treated early, 92% of cases are cured. There are many types of colorectal cancer screening tests, but cancer specialists, such as

the American Cancer Society and doctors at Huntsman Cancer Institute, recommend colonoscopy as the best way to screen for colon cancer for people with a family history. They also recommend that people with a family history like yours should begin having colonoscopy by age 40 (or 10 years earlier) and to have colonoscopies every 3-5 years".

C. High perceived response efficacy

- Affirm their belief that colonoscopy may be beneficial by referring to scientific evidence about effectiveness of colonoscopy and medical guidelines supporting its use.
 - Ex. "You are right. Colonoscopy is very effective in both preventing and detecting colon cancer because it allows the doctor to check your entire colon in great detail for polyps or growths that may develop into cancer. Removing these polyps can prevent colorectal cancer from developing. As we discussed earlier, when colorectal cancer is detected and treated early, 92% of cases are cured. There are many types of colorectal cancer screening tests, but cancer specialists, such as the American Cancer Society and doctors at Huntsman Cancer Institute, recommend colonoscopy as the best way to screen for colon cancer for people with a family history. They also recommend that people with a family history like yours should begin having colonoscopy by age 40 (or 10 years earlier) and to have colonoscopies every 3-5 years".

4. IDENTIFY READINESS TO GET SCREENED

After addressing perceived susceptibility, perceived severity, and response efficacy, in this section, counselors will reevaluate the participants' readiness to change using importance and confidence rulers that will help determine if participants have adequate motivation to change and if they have the confidence and ability (self-efficacy) to do so.

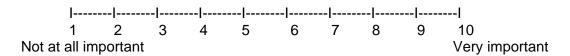
<u>Purpose:</u> The primary goal is to elicit participants' readiness to get screened (e.g., to focus on the motivation the person *already* has). Using information from the previous two sections, as well as the participant's own responses in this section, the goal is to help the person voice the reasons for change and some possible ideas around change.

<u>Strategies:</u> Use the "importance" and "confidence" rulers to elicit the participants' own reasons for wanting to get screened and thoughts about how they could get screened.

Steps:

1. Ask about the importance of getting screened in the next 6 months.

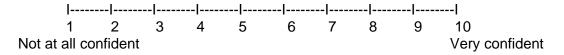
"On a scale from 1-10, how important is it for you to get a colonoscopy in the next 6 months when 1 is not at all important and 10 is very important?"



- If high level of importance (e.g., 5-10):
 - Reflect
 - "It's very/pretty important to you."
 - Ask the participant to elaborate on the reasons for importance
 - "What things make it important for you to get screened?"
 - Refer to family influence by asking questions such as "How is family an important reason for you in getting screened?"
 - "Why an xx and not a lower number?"
 - "What else?"
 - Try to elicit and reflect 2-3 of the participants' own reasons.
- If low level of importance (e.g., 2-4):
 - Reflect answer and ask why they did not choose an even lower number.
 Focus on the motivation they do have, rather than what they lack
 - "So it's a little on the low side, but I'm curious. Why not a 1? So one reason it's important is..."
 - Try to elicit and reflect 2-3 of the participants' own reasons.
 - Refer to family influence by asking questions such as "Why family is an important reason for you to get screened?" If the person doesn't mention family as an important part of their motivation, ask: "I'm wondering how your family fits into your thinking about screening." Reflect and summarize.
- If a one (e.g., not important at all):
 - Reflect
 - "It's not that big a deal to you."
 - "There are other things that are more important to you."
 - Refer to family influence by asking questions such as "Why is family an
 important reason for you to get screened?" If the person doesn't mention
 family as an important part of their motivation, ask: "I'm wondering how your
 family fits into your thinking about screening."
 - Reflect and summarize.

2. Ask about confidence in getting a colonoscopy in the next 6 months.

"On a scale from 1-10, how confident are you that you could get a colonoscopy in the next 6 months if you wanted to when 1 is not at all confident and 10 is very confident?"



- If <u>high level of confidence</u> (e.g., 5-10)
 - Reflect
 - "So you are very/pretty confident you can get screened."
 - Ask for elaboration:
 - "Why is that?"
 - "How would you go about it?"
 - "What would you getting a colonoscopy look like? Who would be helpful to you?"

- Try to elicit and reflect 2-3 reasons why the participant is confident.
- If confidence is medium/high, counselors ask about barriers to screening, ask how important the barriers are to participants, and if they already have a plan to deal with them.
- Discuss possible barriers and how to resolve them (see Appendix A for details of strategies to overcome specific barriers).
- Focus on getting the person to develop the plan by outlining the steps they will take to move ahead and establish a timeline. These steps are on page 4 of the visual aids sent to participants.
- If low level of confidence (e.g., 2-4)
 - Reflect answer and ask why they did not choose an even lower number.
 Focus on the confidence they do have, rather than what they lack.
 - "I see you chose a 3. Why not a 1? What else"?
 - "What would it take to raise your confidence to [one number higher]?"
 - "How would you go about that?"
 - "Who would be helpful to you?"
 - Try to elicit and reflect 2-3 reasons why the participant is not so confident.
 - Discuss barriers and ambivalence about moving ahead with colonoscopy.
 Ask why they are not sure if they can have a colonoscopy.
 - Discuss family influence to encourage participants to seek help from other family members and to help other members to get screened.
 - Outline the steps they will take to move ahead and establish a timeline (see the next section).
- If a one (e.g., not confident at all)
 - Ask what it would take to raise their level of confidence.
 - "What would it take to get you to a little higher confidence level?"
 - "How would you go about that?"
 - "What things have been helpful to you in the past?"
 - Discuss barriers and ambivalence about moving ahead with colonoscopy. Ask why they are not sure if they can have a colonoscopy.
 - Discuss family influence to encourage participants to seek help from other family members and to help other members to get screened.
 - Outline the steps they will take to move ahead and establish a timeline.

Summarize the person's most important reasons for getting screened and confidence to get screened.

5. BARRIERS COUNSELING AND ACTION PLAN

<u>Purpose:</u> To help participants overcome their important barriers to getting a colonoscopy and to assist participants in constructing their action plan for having a colonoscopy

A. Discussing important barriers

• Discuss barriers participants indicated in the baseline questionnaire or that they bring up during the session.

 Develop strategies for each participant to overcome barriers (see Appendix B for specific strategies)

Introduction: Ex. "People have different reasons why they don't get screened. Some people don't have insurance or transportation, while others are wary of the procedure itself. Would it be okay to talk a little bit about some of the things that keep you from getting screened? I may be able to help if you are interested. (If yes) On the survey, you indicated that..."

B. Constructing an action plan to get colonoscopy

- Provide a quick summary of the previous sections, especially people's stated reasons for wanting to be screened, and perceptions of confidence.
- If it is unclear whether the person wants to develop a plan, ask a question to determine readiness to proceed to planning, Ex: "So what would you like to do about this?"
- If the person doesn't want to proceed, skip this section (move to closing)
- If the person would like to proceed, continue this section:

Strategies:

A. Ask about their plan. Reflect and summarize.

- "If you were to get a colonoscopy, how would you go about it? What would be the first step"
- "For most people, the first step involves making an appointment with their doctor.
- "What would that look like for you?"
- "What's the next step for you?"
- "What's your plan?"
- "How will you do that?"
- "Who would help you?"

B. Create Action Plan. (Figure 8; visual aid page 4)

Counselors will refer to the visual aid that has an action plan table (it should be
noted that the participant will not have a date but that the colonoscopy should be
done within the next 2-4 months). Encourage participants who are ready, to
make a plan by saying things like "If you do not have an appointment to have the
screening test and you want to have it, you are more likely to have it if you decide
now on the arrangements you need to make to get an appointment."

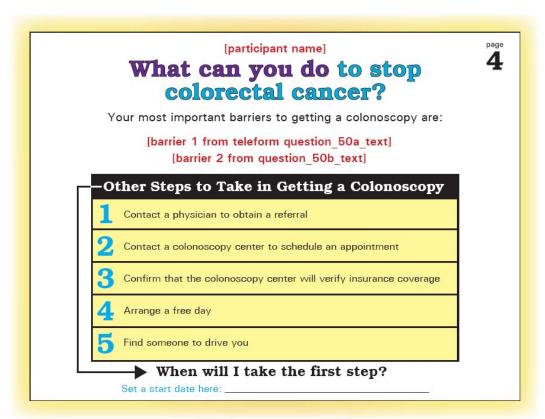


Figure 8. Visual aid: Action plan for participants

- Use implementation intention strategy to construct the action plan: ask patient to specify when, where, and how they will implement each step that is necessary to get a colonoscopy.
- For participants who are not ready to create an action plan (e.g., those who are ambivalent or resistant about getting a colonoscopy), the following strategies may be used.
 - <u>Ambivalent participants:</u> For participants who have mixed feelings about having a colonoscopy (e.g., "I know I should get one but..."), the counselor might focus on reflecting on reasons they should have a colonoscopy and encourage the participant to talk more about the reasons they should get or benefits of having a colonoscopy.
 - If participant agrees to make a plan: Encourage the participant to identify their own solutions to their self-reported barriers.

 Examples for doing this would include: 1) asking them to think hypothetically about how they would go about getting a colonoscopy if they wanted to get one, 2) using confidence ruler. If participants give a low score when asked about their confidence in their ability to get a colonoscopy, this could be followed up with, "So, what would it take to raise your confidence one number from a xx (a number given on the confidence ruler), 3) present the participant with options that other people have considered, "When some people are unsure about whether or not they want to go about getting a colonoscopy they may try calling their insurance company to see if the procedure would be covered or talk to their

doctor about getting a referral or talk to a friend or family member who has had a colonoscopy to see what it was like for them. Do you think any of those things would be helpful for you?" These options should be emphasized as easy to be adopted and presented as ways to get more information for ambivalent participants to make a good decision about how to reduce their risk for colorectal cancer. Depending on how ready participants are, ambivalent participants may or may not be ready to commit to a plan to get a colonoscopy. The counselor might emphasize those options as ways to get more information, not a plan to get a colonoscopy if participants are not ready. The counselor may also mention that colonoscopy is reimbursed by most insurance companies for people with family histories like theirs.

- If participants do not want to make a plan: The counselor may explain the visual aid on page 4 and discuss some options that other people have considered, "When some people are unsure about whether or not they want to go about getting a colonoscopy they may try calling their insurance company to see if the procedure would be covered or talk to their doctor about getting a referral or talk to a friend or family member who has had a colonoscopy to see what it was like for them. We hope this information would be useful to you when you decide to make your own plan to get a colonoscopy. I'm wondering when the time is right, how would you go about it? Give me some examples of what you would do." The counselor then supports their rough plan by emphasizing benefits and ease of performing the behavior (e.g., calling their physician or talking to their family member is an easy way to start it).
- Resistant participants: These are participants who are not ready to change either because they think getting a colonoscopy is not important, colonoscopy is not effective in preventing colorectal cancer (issues of importance), or because they are not able to get it (confidence issue). Therefore, asking them to commit to an action plan may not be practical or appropriate.
 - If the resistance comes from low importance. If participants still believe that having colonoscopy is not their priority, a counselor might only explain the action plan table on page 4 of the visual aid and offer contact information if they want more information about colorectal cancer and screening. The counselor may also ask if participants have any other plan to manage their increased risk for colorectal cancer. If appropriate, the counselor may consider bringing up FOBT as a screening option that is less time-consuming, less obtrusive, less expensive, and easier to get (not as an optimal screening but better than no screening).
 - If the resistance comes from low confidence (e.g., financial barrier). If it's clear that participants cannot get a colonoscopy because some important barriers that they cannot overcome (most likely, the cost of colonoscopy) then the counselor will bring up FOBT as an option and emphasize that screening with FOBT is better than no screening at all

6. CLOSING

At this final step, counselors will:

- Review and summarize the participants' important reasons to get screened, their confidence, and action plan for getting a colonoscopy.
- Obtain permission from participant to allow study to send their physician the tailored letter that contains their family history and risk information, action plan and colonoscopy recommendation.
- Inform participants that they will receive a follow-up letter and written action plan that
 they just developed within a week and a survey in a few weeks. Underscore the
 importance of completing the survey and encourage the participant to do so.
- Ask if they have any questions or concerns
- Emphasize personal responsibility and thank the participant for speaking with you. If appropriate, restate that colonoscopy saves lives.
 - If the participant has already made an action plan to get screened: Ex. "We are glad that you've taken a great step to protect yourself from getting colorectal cancer. We hope that you will follow the plan to get screened. Remember that colonoscopy saves lives and the next move is yours. I appreciate you speaking with me, and I wish you well."
 - If participants do not create an action plan: Ex. "It's clear you've thought a lot about this, so I hope you will make the decision that is right for you and your family. I appreciate you speaking with me, and I wish you well.

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Appendix A: Pre-Intervention Patient Synopsis

General Health Information			
Age			
General Health			
Smoking Status			
Diabetes			
Arthritis			
Hypertension			
Heart Attack			
Depression			
COPD			
Other Screening			
General Physical			
Dental Exam			
Blood Pressure			
Mammogram			
Pap smear			
PSA			
Digital rectal exam			
Previous colon cancer screening			
Risk Perception			
Compared to others			
Percent risk			
RBD Score	Perceived susceptibility=		
	Perceived severity=		
	Perceived efficacy=		
	Self-efficacy=		
Insurance			
Type of insurance	Primary:		
	Secondary:		
Qualify to receive free health care			
services?			
Coverage of colonoscopy?			
Barriers	Ta		
Barriers	1.		
	2. Other barriers:		
Family Influence	Other barriers.		
Members of my immediate family want			
me to have CRC screening			
Members of my immediate family			
encourage me to have CRC screening			
I have a family member or close friend			
who can take me to a colonoscopy			
PCP			
Nearest endoscopy centers			

Appendix B: Specific strategies to overcome each barrier

Barriers	Examples of Tailored Messages
1. I don't have a doctor Strategies: 1. Explore how the participant is getting other forms of medical care and whether the patient had a regular doctor in the past 2. Determine the participant's insurance situation. If uninsured, refer to HCI Hope Line to help them locate a doctor in their area.	"Finding a doctor is important not only for colorectal cancer screening, but for your overall health. We encourage you to look through your insurance information and find a provider in your area. Through the study, we can also help you find resources in your area. To talk with one of our cancer information specialists, please call 877-751-2220."
2. Colonoscopies are embarrassing Strategies: 1. Validate participant's feelings and normalize the participant's hesitation about this procedure 2. Address misconception	"The thought of colonoscopy is embarrassing to most people. However, to doctors this is routine. Rather than feeling embarrassed or ashamed, having a colonoscopy means that you are taking charge of your health and it is a decision you should feel proud of."
3. My doctor has not recommended a colonoscopy Strategies: 1. Address that lack of recommendation does not mean that screening is not important 2. Some doctors may not have the time to identify patients at increased familial risk or discuss colorectal cancer risk and screening. 3. Underscore the importance of being proactive and bringing up their colorectal cancer risk and screening with their doctor	"In taking care of all of a person's general health needs, it can be difficult for doctors to cover all important issues. Through this study we are working with a team that specializes in cancer, and this is our area of focus. We encourage you to bring the information you have learned to your doctor. He/She will most likely agree that this will be very helpful for you and help you take steps to move ahead with scheduling an appointment." We will also send this information to your doctor. Is that okay with you?"

4. I have a busy schedule and don't have time

Strategies:

- 1. Help participant evaluate priorities
- 2. Emphasize that by taking one day to have a colonoscopy, no additional screening will be needed for the next several years

"There never seems to be enough hours in a day to do all that we need or would like to do, (if appropriate) particularly if we have family members (children) that we are taking care of. Taking care of personal health tends to get pushed aside due to other responsibilities. However, in order to be able to take care of your (as appropriate) family, job, farm, etc, you need to first take care of yourself. A colonoscopy will take one day out of your schedule every three to five years. However, treatment of a colon cancer could take time in the hospital to recover from surgery, time to receive chemotherapy and/or radiation, and continued follow-up visits with a doctor for several years. Are their times in your schedule when you may have more time? Are there other family members/co-workers that could help you, so you could make time for this?"

5. I'm scared of the procedure

Strategies:

Determine whether the fear is due to fear of the actual procedures (ex. pain) or of the possibility of finding a cancer, and address appropriately. "Scientific studies indicate that colonoscopies are very safe, and the medication given prevents you from feeling discomfort or from remembering much of the procedures at all. There are situations in which someone may experience discomfort during a procedure. However, these situations are very rare and most people are satisfied with their experience. What is not safe is not being screened. We know that if polyps are not removed, they may progress on to cancer. We also know that cancers are more likely to be cured when it is detected early through screening."

6. I think the colonoscopy is painful or can cause harm and injuries

Strategies:

Clarify why participant holds this belief and tailor message to response.

"Scientific studies indicate that colonoscopies are very safe, and the medication given prevents you from feeling discomfort or from remembering much of the procedures at all. There are situations in which someone may experience discomfort during a procedure. However, these situations are very rare and most people are satisfied with their experience. What is not safe is not being screened. We know that if polyps are not removed, they may progress on to cancer."

7. The cost of colonoscopy is too high

Strategies:

- If the participant is uninsured, refer participant to the HCI HOPE line and encourage them to talk to their doctor about this.
- If insured, discuss current level of coverage and likely out-of-pocket costs for participant
- 3. Help participant put cost in perspective of the potential costs of not screening.
- If colonoscopy is not a financial option, offer the option of FOBT and explain what an FOBT involves.

For those who do not have health insurance and cost of a colonoscopy is a barrier, education should emphasize that FOBT is an alternative and although it may not be as effective as colonoscopy, there is evidence that FOBT saves lives, is much less expensive than colonoscopy, and is better than no screening at all.

"Health care expenses can be very expensive when paying it yourself. However, prevention is often much less expensive than treating a cancer. Our HOPE line may be able to help you locate services to help you. The phone number is on the back of your pamphlet – refer to pamphlet."

Ex. For offering FOBT

"While colonoscopy is the best method for screening, there are other approaches for screening for colorectal cancer such as a stool blood test. This test is not as good as colonoscopy, but it is better than doing nothing and costs less. Like a colonoscopy, a stool blood test can save your life."

8. I believe I am healthy so colonoscopies are unnecessary

Strategies:

- 1. Review that polyps and early stage colon cancers may not cause symptoms
- Waiting until symptoms occur will likely result in the detection of a later onset colon cancer

"As we discussed before, most polyps do not cause symptoms, and waiting until symptoms occur may result in an advanced cancer. When you are healthy is the perfect time to have a colonoscopy because it is most likely that if anything is detected, it will be at an early stage and easily dealt with. If polyps are detected, they can be removed during the colonoscopy – in this way, cancer can be prevented."

9. I'm worried about preparation for getting a colonoscopy

Strategies:

- 1. Address misconceptions about the prep
- 2. Put the minor discomfort associated with the prep into the context of the important gains in preventing colon cancer.

"The prep is unpleasant, but millions of people are able to successfully complete the preparation for a colonoscopy. There are several different preparation options available, and your doctor can help determine which might be best for you. The procedure itself is very safe, and the medication given for the colonoscopy prevents you from feeling discomfort or from remembering much of the procedure. There are situations in which someone may experience discomfort during a procedure. However, these situations are very rare and most people are satisfied with their experience."

10. I would have to drive too far/I don't have transportation

Strategies:

- 1. Help identify the nearest colonoscopy provider
- Use information about family/friend and/or church or other organizational support to help them explore options for identifying someone who can give them a ride

"It looks like the nearest colonoscopy center (s) in your area is X which is about X miles from you. Coordinating a colonoscopy can be even more challenging when you need to make travel arrangements. Do you have access to transportation? Do you have a friend, family, or church member who may be willing to drive or travel with you? Would you be able to combine an appointment with other travel or trips to the area? Is there another area that you travel to regularly that may have colonoscopy services? If yes, where is that? There is a place (s) there that performs colonoscopy. Attempt to help the participant talk out a plan for addressing travel issues."

11. I'm too young to get a colonoscopy

Strategies:

- Address misconception about the age at which colon cancer screening should begin
- 2. Emphasize that even if relatives were diagnosed at old ages, the goal is to begin screening early enough to catch polyps rather than cancer

"While colorectal cancer most often occurs in older individuals, we know that it can commonly occur at younger ages in people with a family history. The people in your family were diagnosed at age... (refer to family history of cancer). We recommend that people with a family history begin at age 40 or 10 years before the earliest diagnosis in the family. This helps to ensure that any problems will be detected at an early stage rather than waiting until the ages when your relatives already had cancers occur."

12. I'm too old to get a colonoscopy

Strategies:

- Address misconception about the age at which colon cancer screening is no longer needed
- 2. Emphasize that colonoscopy is an important way to maintain good health in later years

"Scientific studies have shown that one of the greatest risk factors for getting colon cancer is aging. Cancer specialists still recommend that individuals ages xx years old should have screening colonoscopies."

13. I don't think that colonoscopy works in preventing colon cancer

Strategies:

- This belief would likely have been identified earlier in the session. Continue to try to address misconceptions about the efficacy of colonoscopy
- If participant continues to deny the benefits of colonoscopy, probe further to determine if this is actually the participant's belief or if this is actually another underlying issue (ex. Fear)

"As we have already discussed, scientific studies indicate that colonoscopies can prevent up to as many as 92% of the cases of colon cancer in the US. This means that if we can make people aware of how useful this procedure is, colon cancer will no longer be the third leading cause of cancer related death in the US. Can you please tell me more about why you disagree with this information?"

14. Colonoscopies are disgusting

Strategies:

- 1. Normalize the participant's hesitation about this procedure
- 2. Address misconceptions

"The thought of colonoscopy can be disgusting to some people. However, to doctors this is routine. Rather than feeling embarrassed or ashamed, having a colonoscopy means that you are taking charge of your health and it is a decision you should feel proud of."

15. I don't know where I can get the colonoscopy

Strategies:

Provide information about the nearest locations for colonoscopy

"It looks like the nearest centers providing colonoscopies would be in X which is about X miles from you. Coordinating a colonoscopy can be even more challenging when also needs to make travel arrangements. Do you have access to transportation? Do you have a friend or family member who may be willing to travel with you? Would you be able to combine an appointment with other travel or trips to the area? Is there another area that you travel to regularly that may have colonoscopy services?" (Attempt to help the participant talk out a plan for addressing travel issues.)

16. I am scared about the possible results

Strategies:

- Confirm whether or not the participant is having any symptoms which may be making him/her feel strongly that the colonoscopy may detect something serious
- Explain that not checking the colon will not prevent development of the cancer.
 The earlier a problem is identified, the more easily it can be treated.

"It is understandable that you might be scared that something as serious as cancer could be found. However, most people who get screening colonoscopies are not found to have cancer. And like we discussed before, if they find polyps during the colonoscopy, those can be removed which will help prevent cancer from ever happening. If they are not removed, they can turn into cancer."

17. I'm worried about what will be done to me in having a colonoscopy

Strategies:

Clarify what they think might be done to them (concern about experiencing pain, concern about being sedated and not in control, etc.) "Scientific studies indicate that colonoscopies are very safe, and the medication given prevents you from feeling discomfort or from remembering much of the procedures at all. Some people are concerned about how they will feel when given the sedation medication and they may worry that they will say something embarrassing to the doctors or to their family members. In general the medications just make people feel sleepy and relaxed. While we don't want you driving after the procedure, the medications wear off quickly and you will be able to interact normally."

18. I'm planning to have other types of test for colorectal cancer

Strategies:

- Determine what other screening participant is planning on pursuing and why
- If participant is considering other screening due to cost, review that colonoscopy is most effective method, but that FOBT is effective and is better than not being screened at all.
- If participant is considering other screening due to preference or recommendations from other health care providers, review that colonoscopy is the best method and that it is a better use of their health care resources.

"Colonoscopy is the most effective approach for colon cancer screening, particularly for people with a family history. However, it is expensive. Stool blood testing is somewhat effective but not as effective as colonoscopy in detecting cancer early. Having an FOBT is better than not having any colorectal screening at all. FOBTs should be done every year. This would be a very reasonable approach for screening until you are able to get established with health insurance."

"Your doctor suggested a flexible sigmoidoscopy. The nice thing about this procedure is that it can be done in the doctor's office without any sedation. However, the downside is that it only looks at about 1/3 of the colon. This means the majority of your colon is not being evaluated. So if you are already taking a day off of work and drinking the prep to clean out your colon, we strongly recommend that you maximize your efforts and have a colonoscopy to check the entire colon."

19. I'm not at risk for colorectal cancer

Strategies:

- Risk perception will have been addressed at the beginning of the session. If the participant continues to feel that they are not at risk for colorectal cancer, try to probe further for the basis of this belief.
- 2. Try to determine whether the participant continues to have misconceptions about the causes of CRC and his/her personal risk, or if it is a form of denial.

"As we discussed before, people with the family history like yours are at higher risk for colorectal cancer. Do you have any reasons to believe that you are not at risk? (Counselors will try to correct any misconceptions that may rise). Why don't you think that you are at increased risk given your family history of the disease? Please tell us more about it" (Counselors will try to help participants to be aware of their own defensive behavior if it's the case).

20. I don't have any symptoms of colorectal cancer

Strategies:

- 1. Review that polyps and early stage colon cancers may not cause symptoms
- Waiting until symptoms occur will likely result in the detection of a later onset colon cancer

"As we discussed before, most polyps do not cause symptoms, and waiting until symptoms occur may result in an advanced cancer that is not curable. When you are healthy is the perfect time to have a colonoscopy because it is most likely that if anything is detected, it will be at an early stage and easily dealt with."

21. My insurance won't pay for colonoscopy

Strategies:

- Ask participant to verify that their insurance doesn't cover colonoscopy
- 2. Discuss current level of coverage and likely out-of-pocket costs for participant
- 3. Help participant put cost in perspective of the potential costs of not screening.
- 4. If colonoscopy is not a financial option, offer the option of FOBT and explain what an FOBT involves.

"We'd like to make sure that your insurance doesn't cover colonoscopy because most insurance plans cover it. So, have you checked if it doesn't pay for your colonoscopy? Health care expenses can be very expensive when paying it yourself. However, prevention is often much less expensive than treating a cancer. Our HOPE line may be able to help you locate services to help you. The phone number is on the back of your pamphlet" (refer to pamphlet, if necessary, offer FOBT)

22. I don't know if my insurance will pay for colonoscopy

Strategies:

1. Encourage participant to check if their insurance plan covers colonoscopy.

"Most insurance plans cover colonoscopy. We would encourage you to check with your insurance company to make sure if your plan covers colonoscopy. The best way would be to call in the customer service number on the back of your card. If you find out that your insurance doesn't cover colonoscopy or the level of coverage still concern you, please call me back at the number 1-877-751-2220"