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Communicating Colorectal Cancer Risk to Average Risk Adults: Examining the Impact on Risk Perceptions and Health Behavior Intentions

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A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy at Virginia Commonwealth University

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This work is dedicated to my girls, Olivia and Natalie. You two are my heart.

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Abstract

COMMUNICATING COLORECTAL CANCER RISK TO AVERAGE RISK ADULTS: EXAMINING THE IMPACT ON RISK PEREPTIONS AND HEALTH BEHAVIOR INTENTIONS

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Background

CRC risk can be reduced though lifestyle modification and regular screenings. Providing CRC risk feedback that promotes preventive behaviors to those at average risk has the potential to significantly reduce CRC morbidity and mortality.

Purpose

The purpose of this dissertation was to examine the impact of CRC risk assessment feedback among adults aged 50-75 with no personal or family history of the disease. The specific aims were to: (1a) test personalized (vs. generic) risk assessment feedback on individuals' risk perceptions and intentions to engage in three risk-reducing behaviors (e.g., physical activity, diet, and screening); (1b) determine if the provision of CRC risk information influences breast cancer risk perceptions and mammography intentions; (2a) examine individuals' accuracy of perceived lifetime risk of CRC; (2b) assess whether improved accuracy following risk assessment was associated with changes in behavioral intentions; and finally, (3) evaluate the use of a unique sampling procedure designed to increase diversity of survey respondents.

Methods

A pre-post parallel, two arm randomized controlled trial examined the effects of providing CRC risk assessment feedback that included lifetime risk estimates and information about CRC risk factors that was either personalized (treatment) or generic (control). N=419 average risk adults between the ages of 50-75 were recruited from a commercial online panel.

Results

There were no differences in risk perception between study arms. Overall participants, perceived lifetime risk of CRC lowered at post-test and seemingly produced a spillover effect in lowered perceived lifetime risk of breast cancer among females. CRC screening intentions increased in both study arms and mammography intentions increased in the control arm. Accuracy of lifetime risk improved at post-test, but was not associated with changes in intentions to perform risk reducing behaviors. Quota sampling acquired a targeted and diverse sample quickly and efficiently.

Conclusion

Communicating CRC risk information to average risk adults can improve CRC risk perception accuracy and enhance colorectal and mammography screening intentions. Risk assessment feedback did not consistently influence intentions to improve diet and physical activity.

CHAPTER 1

INTRODUCTION

Background

Colorectal Cancer

Colorectal cancer (CRC) is the third most common cancer diagnosed in both men and women and second leading cause of cancer deaths overall in the United States (US) [1]. Over 130,000 people will be diagnosed with CRC and approximately 50,000 will die from the disease this year [2]. The chance that a man will develop CRC during his lifetime is 4.7%. The average lifetime risk for men of dying from CRC is 2.0% [3]. In other words, men have a 1 in 21 chance of being diagnosed with the disease and a 1 in 50 chance of dying from it. The average lifetime risks are comparable for women, albeit slightly lower (4.4% and 1.8% of developing and dying from CRC, respectively). These estimates represent average risks for men and women within the overall U.S. population; a given individual's actual risk of developing CRC, however, may vary widely depending on their personal risk factors.

Any attribute, characteristic, or exposure of an individual that increases the likelihood of developing a disease is known as a risk factor [4]. Risk factors are classified as either modifiable or non-modifiable. Non-modifiable risk factors for CRC include demographic characteristics such as age, race, and medical history. For example, the risk of CRC increases with age. Compared to younger aged individuals, the likelihood of developing CRC increases markedly among people aged 45-54 years and older, and is most frequently diagnosed among those aged 65-74 years [1]. CRC is more prevalent among men than women and among African Americans [5]. CRC risk is also greater among those with a personal medical history of adenomatous polyps

(adenomas) or an inflammatory bowel disease (IBD), including ulcerative colitis or Crohn's disease [6]. A familial history of CRC, adenomatous polyps, or other inherited (genetic) syndromes are also risk factors [7]. Although an individual cannot alter their risk based on demographic characteristics, other known factors associated with CRC risk are modifiable.

Epidemiological studies have identified many modifiable factors that influence CRC risk, including lifestyle-related and behavioral characteristics. Specifically, physical inactivity, being overweight or obese, smoking, heavy drinking, and/or certain diets (e.g., high consumption of red and/or processed meats) are associated with an increased risk of CRC [5, 7, 8]. Factors associated with a reduced risk of CRC include a healthy diet including an adequate intake of dietary fiber and folate, fruit, vegetables, and/or dairy products, as well as certain medications (e.g., aspirin and hormonal treatments) [5].

Colorectal Cancer Risk-Reducing Behaviors

Changes in health behavior can substantially reduce CRC incidence and the associated disease morbidity and mortality. The previously described lifestyle and behavioral risk factors can become risk-reducing factors if modified appropriately. For example, steps to reduce the risk of CRC include the following: maintaining a healthy weight; being physically active; consuming a healthy diet; limiting alcohol consumption; and avoiding tobacco products [5]. In addition to the management of risk factors, CRC screening is an important risk-reducing behavior. Screening can prevent disease development through the detection and removal of precancerous lesions [9]. Accordingly, U.S. evidence-based guidelines recommend routine screening for all adults age 50-75 years old [10].[1] The association between modifiable factors and disease risk is

strong; in fact, as much as 70% of CRC cases could be prevented through lifestyle modification and widespread screening [11].

Despite the potential health benefits, most Americans do not engage in a healthy lifestyle. Behavioral risk factors associated with cancer are prevalent in the U.S. general population [12]. For example, almost 80% of American adults do not meet guidelines for physical activity [13]. Sedentary lifestyles combined with an unhealthy diet have led to a dramatic increase in the prevalence of obesity and overweight in the US. As of 2010, two out of three American adults are either overweight or obese [14]. In addition, national CRC screening rates are also suboptimal; over a third of the age-eligible population remain unscreened [15]. The identification and communication of an individual's modifiable risk factors may be an imperative first step in promoting risk-reducing behaviors. However, increased knowledge is not sufficient for behavioral change [16]; improved strategies to promote CRC screening and healthy lifestyles are needed. Specifically, how best to leverage risk factor information to engage people in cancer risk-reducing behaviors remains unknown.

Risk and Risk Presentation

Risk is a concept based on probability; disease risk is the chance that a disease will occur [11]. The term also that implies one possible outcome is negative and that there is some degree of uncertainty as to what the outcome will be [17]. Risk is often expressed in absolute or relative terms. Absolute risk is the chance of disease occurrence over a specific period of time (e.g., 5-year, lifetime, etc.), while relative risk (also known as comparative risk), refers to an individual's risk compared to a reference group (e.g., peers). Absolute and relative risks have traditionally been expressed either numerically (e.g., a 0% to 100% chance) or verbally (e.g., low risk).

Although both absolute and relative risk estimates can be presented in numbers, the resulting representations of risk are quite different. For example, a small increase in the average lifetime risk for CRC (e.g., 4% to 6%) appears much larger when presented using relative risk (e.g., 50% increased risk). For this reason, researchers recommend using absolute risk instead of relative risk to improve the understanding of quantitative risk information [18]. Nonetheless, presenting relative risk may be critical when the goal is to heighten risk perception, which is often the case in behavioral health interventions.

The interpretation of risk information is further complicated by individual factors related to education, health literacy, and numeracy [19]. In fact, approximately two thirds of Americans aged 16 to 65 years do not have the level of numeric proficiency necessary to understand proportions expressed in verbal or numerical form or to interpret basic statistics [20]. In order to facilitate the interpretation of risk information, quantitative risk estimates are sometimes collapsed into categories and expressed in words instead (e.g., average vs. elevated risk). However, this broad representation of risk is less precise than numeric estimates and issues with interpretation persist since verbal expressions of risk such as “likely” or “elevated” can be interpreted in a variety of ways. Recent research has suggested that the presentation of risk in visual formats (e.g., pictographs, pie charts, and stick figures) aids in the comprehension and recall of risk information [21-23]. However, little is known about the effectiveness of using visuals to communicate risk of low probability events [21].

In summary, there is no “one-size-fits-all” best practice for the dissemination of risk information. A personalized approach to risk communication may be best for comprehension accuracy, but identifying the right presentation format for a given individual can be challenging

[17, 24]. Therefore, strategies to communicate risk effectively include presenting risk information in multiple formats (e.g., texts, tables, and graphics) [18].

Risk Perception, Behavior Change Intentions, and Behavior

Risk perception refers to an individual's beliefs about the likelihood of an occurrence of a particular health threat or the likelihood of developing a health problem [25]. Previous research has identified numerous influences that shape risk perceptions, including demographic (e.g., age [26] and race/ethnicity [27-28]), health [26-27], cognitive (e.g., numeracy), and psychological/affective (e.g., optimistic bias and cancer worry [26]) factors. Although a myriad of other factors influencing risk perception have been identified in the literature, research findings are not always consistent. For example, minorities report lower perceptions of cancer risk than Whites in some studies [28-29], while others study have found significant variation in risk perceptions by race/ethnicity [30-31]. The interplay between factors is also important. For example, minorities and older adults tend to have lower numeracy, and numeracy, in turn, can impact one's ability to comprehend risk information [32]. The examination of these complex relationships, differences in research methodologies, such as the type of risk variable evaluated (e.g., absolute vs. relative), composition of study populations, and range of predictors assessed, make it difficult to draw conclusions across studies. Despite these differences, one factor is consistently identified in the literature; family history.

Perceptions of disease risk, including CRC risk, are heavily influenced by a family history of the disease [26, 27, 33]. Recent research has even suggested that a family history of cancer may lead to "spillover" effects of altering the perception of risk for other types of cancer [34]. However, the majority of new CRC cases will develop among "average risk" individuals, those

with no known family history or other predisposing conditions (e.g., familial adenomatous polyposis (FAP) and hereditary non-polyposis colorectal cancer (HNPCC), among others) [35]. Focusing CRC prevention strategies on average risk individuals could impact incidence and also potentially benefit the significant portion of individuals who are unaware of their increased risk status due to having limited or incorrect knowledge of their family health history [36]. Therefore, research examining the factors that influence risk perception among an average risk population is warranted but has received relatively little attention in the literature.

Risk perception and related constructs (e.g., perceived vulnerability, susceptibility, and probability) have been prominent components of behavioral health theories for decades [25]. Widely known theories emphasizing the role of risk perception in influencing behavior include the Health Belief Model [37], the Protection Motivation Theory [38] and the Precaution Adoption Process Model [39-40]. Other more complex theories have been developed to predict response to health risk information specifically, Marteau and Weinman's adaptation of the Common Sense Model (CSM) of Illness Representation [41]. According to this model, health risk information is processed through an individual's cognitive and emotional schemas. These representations of the health threat then influence the development of coping responses (e.g., behavioral change) to reduce the perceived threat. Within most individual-level theories of health behavior change, risk perception serves as a precursor of health-protective behavior change. Specifically, increased perception of risk serves as a catalyst to increase the likelihood of the performance of behaviors to reduce risk. From this perspective, behavioral change intentions are a prerequisite for behavior change. Although discrepancies between intention and behavior can occur [42], cancer screening intentions and attending screening are often correlated [43]. The

present study will focus on behavioral intentions, as assessment of behavior change is outside the scope this study.

The perceived risk of CRC is low among the U.S. adult population [26, 44-45]. For example, 62% of the 2003 Health Information National Trends Survey (HINTS) respondents aged 45 and older with no personal history of CRC indicated their CRC risk was somewhat or very low, while far less endorsed being at moderate (30%) or somewhat high/very high risk (8%) [26]. Based on these empirical findings and the aforementioned theoretical conceptualizations (e.g., the Health Belief Model, etc.) of risk perception, behavioral interventions often focus on increasing individuals' perceptions of risk. The purported positive association between perceived risk and risk-reducing behavior is generally supported, albeit often with relatively small effect sizes [46-48]. A recent meta-analysis of experimental studies, however, found that heightening risk appraisals (a composite variable comprised largely of perceived risk) had a medium effect on behavioral outcomes overall (d_+ = 0.31 (k = 217), with larger effect sizes observed for dietary behaviors (d_+ = 0.46 (k = 11) and exercise (d_+ = 0.38 (k = 8) [49] – both modifiable lifestyle characteristics and key factors in cancer prevention [50]. In contrast, at least one study using cross-sectional, nationally representative data found no associations between perceived cancer risk and diet and exercise behaviors [51].

Among research on CRC screening behavior specifically, risk perception generally seems to encourage preventive behaviors as predicted by theories of health behavior. For example, a seminal review by Vernon and a more recent analysis of cross-sectional, nationally representative data, provide evidence that individuals who report greater perceived risk of CRC are more likely to screen than those who report lower CRC perceived risk [52-53]. Similarly, a

recent systematic review and meta-analysis of 58 studies by Atkinson and colleagues observed a small, positive, and statistically significant relationship between CRC risk perception and screening use [54].

In addition to examining CRC behavioral intentions following the provision of risk estimates for colorectal cancer, the proposed study will assess change in women's breast cancer risk perceptions and mammography screening intentions. Previous research has identified "spillover" effects where a family history of one cancer was associated with altered risk perception for another [34]. However, it is not known whether cancer-specific risk results could produce similar effects on the perceptions of risk and screening intentions for other cancer types that share similar lifestyle based modifiable risk factors. This information could have important implications for cancer risk assessments.

In conclusion, the equivocal findings related to CRC risk perception and behaviors overall may be due, in part, to a variety of factors such as disparate measures of perceived risk and issues related to risk perception accuracy. There is no "gold standard" instrument for assessing risk perception [55]. Although a new, multidimensional measure of risk perception was published in 2016 [56], the most commonly used measures consist of relatively few, face-valid questions, such as the HINTS survey items. In fact, the majority of the 58 studies reviewed in a recent meta-analysis of the literature examining risk perception and CRC screening measured CRC risk perception using a single item (64%) [54]. Moreover, type of risk used in the research reviewed was most often expressed verbally in relative (36%) or absolute (36%) terms, with far fewer studies employing numeric absolute or a combination of risk types (7 and 21%, respectively). Some experts assert that there are likely at least two dual processes at play in the

comprehension of risk information (e.g., cognitive/analytical/deliberative vs. affective/experiential/intuitive) [27, 57-59]. However, it has been noted that the affective system is likely to be more relevant among individuals with either a family history or symptoms of disease, compared to average risk groups [27]. Different measurements could also be the source of biased judgments about risk perceptions. For example, laypeople have been shown to overestimate their risk when assessing their CRC risk using numeric scales [60]; thus, categorical response options may be preferable. Alternatively, inaccurate risk perceptions present in research samples may be a reflection of the underlying difficulties laypeople have in the comprehension of numeric risk information related to numeracy. Providing cancer risk information may help correct risk perception inaccuracies and subsequently, drive intentions for preventive health behaviors more uniformly.

Cancer Risk Assessment Tools

As our understanding of cancer etiology and risk factors has advanced, growing numbers of risk estimation/prediction models and assessment tools, hereafter referred to jointly as risk assessment tools (RATs), have been developed to predict the occurrence of cancer and guide approaches to disease prevention [61]. RATs calculate an individual's cumulative risk from multiple sources, including individual characteristics and behaviors, family history, and population-based estimates. A well-known use of RATs is to help clinicians identify individuals who are at high risk of cancer and thus enable risk-stratified recommendations for screening and disease prevention.

Three recent reviews have been published summarizing the extant CRC RATs [50, 62-64]. Although specific model evaluations are beyond the scope of this study, the discriminatory

power of CRC RATs in general is regarded as comparable to other cancer risk models. There is heterogeneity among RATs in the array of risk factors included, sources of data used in model development (e.g., cohort vs. case-control studies), and outcomes predicted (e.g., subtypes of CRC). Moreover, most have not been validated in diverse populations. There is no single best RAT; each has unique strengths and limitations and provides varying risk types (e.g., absolute or relative) and presentation formats (e.g., with or without visuals). A content analysis of available internet-based cancer RATs was conducted in 2009 [65]. Among the 47 RATs identified, 10 (21%) provided colorectal cancer risk information. Among all websites providing assessments, very few used risk communication formats that facilitate comprehension and reduce bias. For example, while the majority of sites were intended for lay audiences (89%), 83% contained undefined terminology (e.g., biopsy); and only five websites used both words and numbers to communicate risk. However, approximately one-third of sites provided at least one visual display, and one-half provided duration of risk (e.g., 5-year risk). This study suggests that online RATs have room to improve in conveying health risks. Despite these shortcomings, cancer RATs are becoming increasingly available to the public via online sources.

Online Colorectal Cancer Risk Assessment Tools

Among the several CRC RATs available online [66-70], perhaps the two most well-known are those developed by the Harvard Center for Cancer Prevention [70] and the tool made publically available by the NCI [67]. Both are easily accessible and frequently used in clinical and research settings. The tool that began as the Harvard Cancer Risk Index (HCRI), now available on the Your Disease Risk site [70], was one of the first calculators developed to predict individual cancer risk [71]. The current, easy-to-use online Your Disease Risk RAT predicts

relative risk; providing results in both verbal categories (e.g., below average) and a graphic representation. The HCRI also provides feedback on the risk-reducing behaviors respondents are already doing and specifies behaviors they could do to lower their risk. HCRI results, however, do not provide numeric risk estimates, which is a recommended format for communicating risk [18]. The NCI's Colorectal Cancer Risk Assessment Tool (CCRAT) [67] was developed by Freedman and colleagues [72-73]. Results of this internet-based tool provide multiple numeric risk estimates and in addition, an invariant, bulleted summary of factors that can increase and lower CRC risk. The factors appearing on the list are not based on assessment responses and thus, may not apply to every respondent. For example, obesity is listed as risk factor, regardless of whether the respondent is normal weight, overweight, or obese.

Although RATs are widely used in clinical practice, little is known about how risk feedback affects average risk individuals and those who access these tools online. Since the perceived risk of CRC is low in the general population [26, 44-45], RAT results that afford even average risk estimates could conceivably help individuals gauge their risk more accurately and motivate preventive health behaviors. However, little is known about the application of cancer risk prediction models for population approaches to cancer prevention or the use and utility of online cancer RATs among laypeople. A 2004 NCI-sponsored workshop on cancer risk prediction models highlighted their potential utility to facilitate both high risk and population level approaches to cancer prevention [61]. Workshop participants specifically expressed that since most cancers occur among individuals with approximately average individual risk, strategies for reducing lifestyle risk factor prevalence in the general population would yield maximum benefits. They also called for future research on how to effectively communicate risk to the

general public outside of the doctor-patient encounter. Additional research is needed to determine if the provision of RAT results will similarly alter risk perception among average risk individuals (e.g., excluding those with a family history of CRC in additional to those with a personal history) and whether RAT results influence cancer control-related behavioral intentions, including diet, physical activity, and screening.

To my knowledge, only one study has examined the impact of CCRAT risk information on interest in CRC screening among lay individuals [74]. This study by Han and colleagues included a convenience sample of adults aged 51 years and older from the general public who accessed a website with a fully functional replica of the CCRAT. Although no main effects were found between CRC risk information and interest in screening, results revealed different interest in CRC screening subgroups, depending on prior screening history, estimated cancer risk, and baseline screening interest. CCRAT results provided in this study did not include the non-quantitative, risk factor summary section. Therefore, it is unclear whether additional information on risk factors could impact interest in risk-reducing behavior. A 2006 Cochrane review concluded that personalized risk information mobilizes health behavior change [75]. Therefore, the utility of the CCRAT is potentially limited since the risk factor summary it provides is not personalized.

The addition of personalized feedback on an individual's risk factors and related lifestyle changes that would reduce their risk may help improve awareness related to cancer prevention within the general population, including the roughly 32 million Americans who believe nothing can reduce an individual's cancer risk [76]. In addition to increasing awareness about risk factors, the utility of the CCRAT may be enhanced as the use of individually-tailored behavior

change information during a health risk assessment has previously been shown to promote health behaviors [77]. Risk assessment results providing both numeric risk estimates similar to the CCRAT and concrete, actionable behavior change recommendations corresponding to each risk factor, such as those provided by the *Your Disease Risk* tool, may produce more meaningful feedback. This may be especially true for average risk individuals, for whom no intensified preventive approaches apply. However, it is not known what, if any, beneficial changes in risk perceptions and intentions for behavioral change would result from this integrated format of risk factor feedback. The current study will explore this question and address this gap in knowledge needed to inform the future development and improvement of CRC RATs.

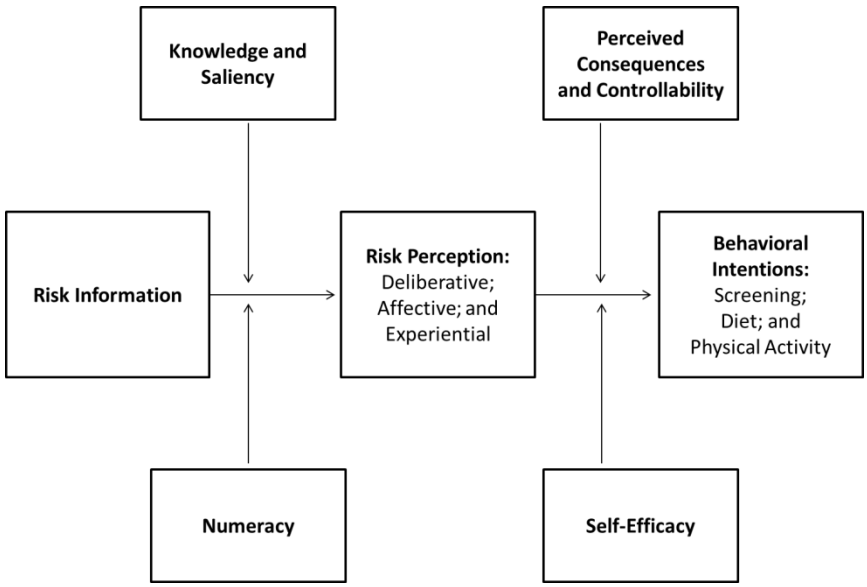
Conceptual Framework

The overarching conceptual framework guiding this study draws from the Common Sense Model (CSM) of self-regulation of health and illness [78]. This longstanding theoretical model has been used to understand the impact of risk information related to a health threat (instead of an illness) [79-80]. Consistent with other research [79], the cognitive processing components of the CSM (i.e., stimuli, representation of health threat, and coping) are conceptualized as risk information, risk perception, and behavioral intentions.

As shown in Figure 1, the communication of risk information influences risk perceptions, which in turn, drive behavioral intentions to manage risk. Specifically, it is theorized that information about risk that is tailored to an individual's actual risk factors and provides a personalized behavior change recommendation to reduce risk will heighten risk perceptions and subsequently, result in greater health behavior change intentions (compared to generic information) [81-82]. Knowledge and saliency of risk factors are depicted as influencing

(moderating) risk perception following the receipt of risk information, and attitudes (perceived consequences) and behavioral beliefs (perceived controllability) about cancer prevention are conceptualized as moderating factors between risk perception and behavioral intentions. In addition, numeracy and self-efficacy are included in the framework and will be controlled for in the final analyses.[2]

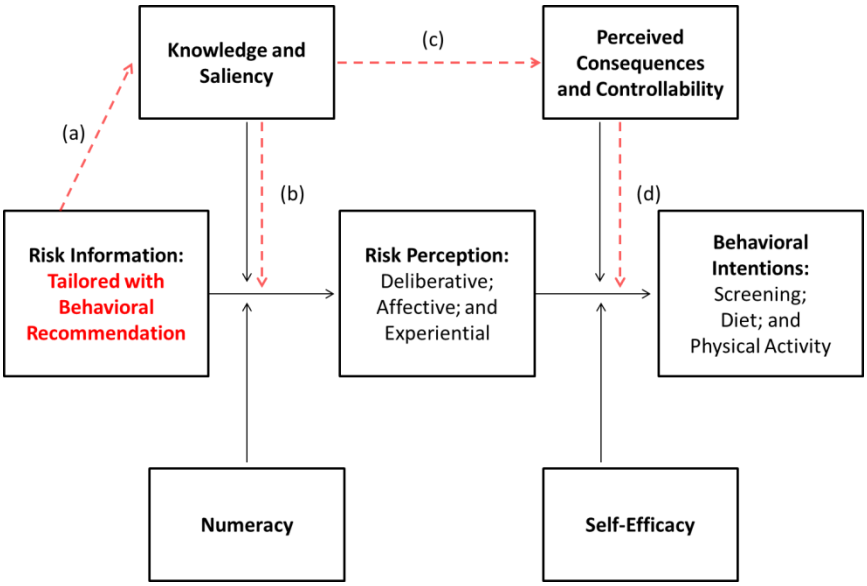
Figure 1a. Overarching Conceptual Framework



Within the treatment arm specifically, in which the risk factor summary is tailored to the individuals' actual risk factors and provides a personalized behavior change recommendation to reduce cancer risk, the hypothesized pathways of causal mechanisms are shown in Figure 1b below in red arrows. First, the provision of personalized risk information is expected to increase knowledge about cancer prevention and saliency of risk factors significantly, compared to the generic feedback provided in control arm (a). Higher levels of risk factor knowledge and

saliency will subsequently enhance risk perceptions (b). Previous research supports the assertion that tailored messages are considered more relevant and result in greater health behavior change, compared to generic communication. In addition, increased knowledge on how to reduce risk will logically alter attitudes and beliefs about cancer prevention (perceived consequences and controllability) (c). Finally, more informed attitudes and beliefs about cancer prevention will then promote higher behavior change intentions when combined with already heightened risk perceptions (d).

Figure 1b. Conceptual Framework: Treatment Arm



Research Aims

The primary focus of the present dissertation was to examine the impact of CRA feedback on CRC risk perceptions (primary outcome) and behavioral intentions (secondary outcome) among an average risk adult population. This research builds on previous risk communication

studies suggesting that personalized information about risk factors is more effective than generic, non-personalized information in enhancing risk perception accuracy [60, 83] and cancer screening utilization [75, 84]. The specific aims of the primary paper of this dissertation were as follows:

Aim 1: Experimentally evaluate the effects of providing personalized (vs. generic) information on CRC risk factors on risk perceptions and behavioral intentions among an average risk adult population.

Hypothesis 1: Risk perceptions will be higher among those who receive personalized information, compared to generic.

Hypothesis 2: Behavior change intentions will be higher among those who receive personalized information, compared to generic.

Aim 2: Explore whether the provision of CRC risk information alters breast cancer risk perceptions and mammography screening intentions among female participants.

Hypothesis 3: Breast cancer risk perception will be higher among those who receive personalized information, compared to generic.

Hypothesis 4: Mammography screening intentions will be higher among those who receive personalized information, compared to generic.

The existing body of research on CRAs has shown improved risk perception accuracy following risk assessment feedback [60, 83, 85-86]. However, few studies have evaluated the impact of CRA feedback on average risk individuals (i.e., individuals with no known history of CRC). Advanced approaches to CRC prevention including strategies aimed at the entire at-risk

population may be particularly important given the high prevalence of modifiable risk factors in the general population and because intervening with the populace would yield more cumulative benefits than focusing on those at high risk alone. Since perceived risk of CRC is low [26, 44-45] and the actual risk of CRC of someone at average risk is relatively low, it is unclear if improving risk perception accuracy would be beneficial (e.g., promote risk reducing behaviors) or detrimental (i.e., foster a false sense of security that hinders the adoption of preventive behaviors). Thus, research is needed to assess factors associated with post-CRA lifetime risk perception accuracy and the behavioral implications of altering accuracy among average risk individuals. Accordingly, the second paper of this dissertation addressed this gap in knowledge through the following aims:

Aim 1: Characterize perceived lifetime risk prior to CRA feedback.

Aim 2: Examine predictors of baseline perceived lifetime risk accuracy.

Aim 3: Identify predictors of improved risk perceptions among those who were inaccurate at baseline.

Aim 4: Assess whether improvement in perceived lifetime risk accuracy was associated with changes in behavior change intentions for physical activity, diet and attending CRC screening.

In addition to these research aims, this dissertation sought to characterize the validity of the online panel sample utilized in the present research. Understanding the strengths and potential pitfalls of using online panels is critical to making informed decisions about research strategies,

especially when targeting groups typically underrepresented in research samples, such as minorities and older adults. Thus, the specific aims of the final paper were to:

> Aim 1: Describe the recruitment and participant flow of a survey administered by a commercial research platform using quota sampling.
>
> Aim 2: Describe the sociodemographic characteristics of eligible respondents that complete the survey and respondents that initiate, but do not complete the survey.
>
> Aim 3: Compare sociodemographic profiles of survey completers to respondents that initiate, but do not complete the survey.
>
> Aim 4: Determine when study-eligible non-completers exit the survey.

Results of this dissertation afforded valuable insights into the potential utility of CRAs to alter risk perceptions and drive risk-reducing behaviors. Findings provided insight regarding which participants benefited from improved accuracy after receiving CRA feedback and how behavioral intentions were impacted as a result of improved accuracy. The sampling methods used in this study were also examined. Such information is imperative to the improvement and development of the next generation of CRA tools, as well as to the design of interventions to improve cancer preventive behaviors.

Footnotes

[1] CRC screening guidance referenced in this study was based on that provided by the U.S. Preventive Services Task Force, which remains the same at the time of this dissertation draft. However, it should be acknowledged that the American Cancer Society updated their guidelines in 2018, recommending that those at average risk of CRC should screen regularly between the ages of 45-75 years old – five years earlier [87].

[2] Intervention arm (generic vs. personalized) was not a significant predictor of either risk perceptions or behavioral intentions in multivariate analyses controlling for the other variables in the model. There were also no significant differences in risk perception or other intermediate variables between intervention groups. Subsequently, the moderating relationships proposed in this model, illustrating a causal pathway, were not warranted.

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CHAPTER 2

Paper One

THE EFFECTS OF PERSONALIZING COLORECTAL CANCER RISK COMMUNICATION ON RISK PERCEPTIONS AND HEALTH BEHAVIOR INTENTIONS: A RANDOMIZED TRIAL OF AVERAGE RISK ADULTS

Abstract

Background

Risk assessment tools may help individuals gauge cancer risk and motivate lifestyle changes and other risk-reducing behaviors, such as routine cancer screenings. Despite the evermore common availability of such tools, little is known about the potential utility of risk assessment tools for population approaches to cancer prevention.

Purpose

We evaluated the effects of providing personalized (vs. generic) colorectal cancer (CRC) risk assessment feedback on average-risk individual's risk perceptions and intentions to engage in three risk-reducing behaviors: CRC screening, diet, and physical activity. We also examined whether the provision of CRC risk assessment information alters breast cancer risk perceptions and mammography intentions.

Methods

We administered an accepted cancer risk assessment tool to an online panel sample. N=419 survey respondents aged 50-75 with no personal or family history of CRC were randomized to receive lifetime CRC risk estimates and risk factor information that was either personalized (treatment) or invariant/non-personalized (control). Respondent cancer risk perceptions and

behavioral intentions were ascertained immediately before and after risk assessment administration.

Results

No differences were observed in risk perception or behavioral intentions between groups. However, CRC screening intentions and intentions to talk to a doctor about CRC screening significantly increased in both groups. In addition, within both groups, the average lifetime risk of colorectal and breast cancers reported significantly decreased.

Conclusion

Results support the potential role cancer risk assessment information could play in promoting cancer screening behaviors, while highlighting the known difficulty of using risk information alone to "moving the needle" on lifestyle modifications among individuals without a cancer history. Reductions in perceived lifetime risk of CRC seemed to spillover onto female participants' perceived lifetime risk of breast cancer. How best to leverage benefits from (while minimizing negative impact of) the spillover effects from risk communication targeting one disease on other disease warrants additional consideration.

Background

Colorectal cancer (CRC) is the third most common cancer and second leading cause of cancer death overall in the United States (US) [1]. Over 130,000 people will be diagnosed with CRC and approximately 50,000 will die from the disease this year [2]. The majority of new CRC cases will develop among "average risk" individuals, those with no known family history or other predisposing conditions (e.g., familial adenomatous polyposis (FAP) and hereditary non-polyposis colorectal cancer (HNPCC)) [3]. The association between modifiable factors and CRC risk is strong; as much as 70% of CRC cases could be prevented through lifestyle modification and widespread screening [4]. Therefore, modifying behavioral risk factors within the average risk population could substantially reduce CRC incidence and associated morbidity and mortality.

Lifestyle factors such as maintaining a healthy weight, being physically active, consuming a healthy diet, limiting alcohol consumption, and avoiding tobacco products can reduce the risk of CRC [5-6]. CRC screening is another important risk-reducing behavior as it can prevent disease development through the detection and removal of precancerous lesions [6-8]. Despite the potential health benefits, most Americans do not engage in CRC risk-reducing behaviors. Lifestyle risk factors associated with cancer are prevalent in the U.S. general population [9-10]. The identification and communication of an individual's modifiable risk factors may help individuals gauge their CRC risk and motivate intentions to engage in lifestyle and other risk-reducing behaviors, such as routine cancer screenings. Cancer risk assessment tools that convey this information are increasingly available to the public online [11]. Although evidence suggests online risk assessment tools are a promising approach for communicating risk and promoting

health behaviors in high risk individuals [12-14], little is known about the application of cancer risk assessments for population approaches to cancer prevention among those at average risk.

Another unknown outcome of cancer risk assessments is what influence, if any, receiving risk information for a specific cancer type has on risk perceptions and behavioral intentions related to another cancer type. An earlier study by Rubinstein and colleagues identified "novel spillover effects" whereby having a family history of one cancer was associated with altered disease perceptions of another cancer type [15]. Therefore, it is conceivable that heightened perceived risk for one cancer (following receipt of risk assessment results for that cancer type) may alter an individual's perceived risk and behavioral intentions related to another type of cancer (via spillover effects). Therefore, conceptually, a single intervention could be designed to improve multiple risk behaviors. This hypothesis has not been scientifically evaluated.

While communicating risk may be an important step in shaping perceptions of disease risk, providing risk estimates alone may not be enough to drive health behaviors and behavior change intentions [16-22]. This may be especially true among individuals without a known family history who receive low or average numeric (e.g., <5%) or categorical (e.g., "unelevated") risk estimates. When targeting individuals who do not have a known family history of cancer, it may be particularly important to increase information saliency by incorporating personalized information designed to heighten risk perception, and ultimately, drive behavioral change intentions.

Personalized risk communication, including information tailored to individuals' unique risk factors has been shown to increase accuracy of risk perceptions [23-24] and mobilize cancer screening utilization [25-26]. Another study similarly found improvements in breast cancer risk

perceptions and physical activity intentions within the personalized condition (compared to non-personalized) [27]. To our knowledge, no study has compared the effects of providing CRC risk feedback with personalized feedback (compared to generic) regarding risk factors, in addition to personalized risk estimates (e.g., lifetime risk), on behavioral intentions as well as risk perceptions among average risk individuals.

The primary objective of this study was to experimentally evaluate the effects of providing personalized (vs. generic) information on CRC risk factors on risk perceptions and behavioral intentions among an average risk adult population. In secondary analyses, we also explore whether the provision CRC risk information alters breast cancer risk perceptions and mammography screening intentions among female participants. Consistent with the evidence favoring personalized risk communication [28], the primary hypothesis of this study was that (H1) CRC risk perception will be higher among those receiving personalized information, compared to the control. Secondary hypotheses also assessed were that compared to controls, (H2) behavior change intentions regarding CRC screening, healthy diet, and physical activity will be higher among treatment participants; and among female participants, (H3) breast cancer risk perception and (H4) mammography screening intentions will be higher among treatment participants.

Methods

Study Design

We used a pre-post parallel trial design to evaluate the effect of providing personalized risk factor information. An online survey was administered through Qualtrics, an internet-based survey and research company, in June 2017. Participants were randomized to receive either

personalized or generic information on risk factors. Randomization occurred after completing screener items and the pre-intervention survey but prior to the post-intervention survey and remaining demographic items (e.g., marital status, education attainment, and employment status). Randomization was carried out by Qualtrics using the Mersenne Twister algorithm, a commonly used and widely accepted form of random number generation [29-30].

Participant responses to risk perception and behavioral intention questions were collected prior to and immediately following receipt of CRC-specific risk feedback. Prior to beginning the risk assessment tool, participants were queried for information necessary to determine sample eligibility (e.g., age, race, household income, state of residence, and personal and family cancer history), and asked to complete a brief series of questions measuring sociodemographic characteristics including gender, education attainment, marital status, employment status, and insurance status. Baseline (pre-intervention) behaviors were queried to ascertain cancer screening status and to detect the presence of lifestyle risk factors (physical activity and diet) using previously developed items [31-33]. All survey items required a response; therefore, there were no skipped or missing responses. Upon survey completion, participants could select from a variety of incentive options worth approximately $5.00. This study was approved by an Institutional Review Board (IRB) following expedited review.

Sample and Survey Administration

Qualtrics acquired the sample from existing pools of research panel participants.[1] Recruitment targeted potential survey respondents who were likely to qualify based on the demographic characteristics reported in their user profiles (i.e., race and age). Panelists were

invited to participate via email and opted in by activating a survey link that directed them to the study consent form.

Quota sampling was used to obtain a sample that was diverse with respect to household income and race. A balanced sample of White, Black/African American, and Hispanic/Latino/Spanish participants was requested. Respondents identifying as some other race were not eligible to participate. Eligible panel participants included residents of the contiguous U.S. with the ability to read and comprehend English language. In addition, participants were screened for the following eligibility criteria: age 50-75 years old (age-eligible for CRC screening) and no personal or family history of CRC or other predisposing factor (i.e. inflammatory bowel disease, polyps or a hereditary syndrome such as familial adenomatous polyposis (FAP) or hereditary nonpolyposis colon cancer (HNPCC), also known as Lynch Syndrome). Individuals who reported an age outside the range of 50-75 years or any predisposing factor were excluded. In addition, respondents were removed from the survey if they responded incorrectly to any of the three "attention checks" (i.e., survey items that instructed respondents to provide a specific response).

Risk Information

All participants, regardless of study arm, received gender-specific, population-level lifetime risk of developing CRC in the United States (Figure 1) [34]. Risk factor information was presented immediately following the numeric risk estimates, according to study group. Participants randomized to the control group received a summary describing 11 factors that can increase and lower risk of CRC (Figure 2) [35-36]. Within the treatment group, the risk factor

information provided was tailored to each respondent's actual risk profile (i.e., the presence/absence of risk factors as reported by each respondent).

To test the influence of personalized risk factor information on risk perception and behavioral intentions, three modifiable CRC risk-reducing behaviors were chosen (screening, physical activity, and diet). The specific content of the individually tailored risk summary was adapted from the prevention messages provided by existing online risk assessment tools [35, 37-38]. Each targeted behavior was framed as either a risk (Figure 3a) or protective (Figure 3b) factor based on participant reported engagement in that behavior. Any behaviors listed as a risk factor included a behavior change recommendation. Each risk factor message also included information about the consequences of the behavior (i.e., performing this behavior will reduce risk). The wording of these statements was developed based on Prospect Theory [39] and in accordance with prior research demonstrating that gain-framed messages tend to be more effective in promoting prevention behaviors and intentions, including diet [40] and physical activity [41], whereas loss-framed behaviors are more effective in promoting diagnostic behaviors and intentions (e.g., cancer screenings) [42-43]. Table 1 provides the protective and risk message content corresponding to each of the three behaviors.

Outcome Measures

Cancer Risk Perceptions.

The primary outcome, CRC numeric lifetime risk, was assessed by asking, "On a scale from 0 to 100 %, how would you rate the probability that you will develop colorectal cancer in the future?" with an open-response of 0-100%. "How likely is it that you will get colorectal cancer at some point in the future?" was used to assess absolute risk using a five-point Likert scale ranging

from “very unlikely” to “very likely.” Relative risk was also measured with the question, “How do you think your chance of developing colorectal cancer in the future compares to the average person of your gender and age?” with responses ranging from “much lower” to “much higher” on a five-point Likert scale. These three individual items were also adapted to assess perceived absolute, relative, and numeric lifetime risk of breast cancer among female participants.

Dichotomous measures of accuracy were created for reported numeric lifetime risk of colorectal and breast cancers. Accurate lifetime risk of CRC was defined using statistics from the American Cancer Society [2], as a response between four and five percent. The average lifetime risk of women developing breast cancer is approximately 12% [44]; therefore, responses between 10-15% were coded as accurate. The wider range of reported breast cancer risk was considered accurate since no estimates were provided to respondents.

Behavior Change Intentions.

Behavior change intentions related to CRC screening, mammography screening, physical activity, and diet, as well as intentions to talk to a doctor about getting tested for CRC, were assessed at pre- and post-intervention. Based on previous CRC screening research [45], respondents were asked a single item adapted for each behavior, “How likely are you to [get screened for colorectal cancer, improve your diet, and increase your physical activity] in the next 6 months?” on a five-point Likert scale “not at all to “extremely.” Participants classified as up-to-date on CRC or mammography screening based on their prior responses about screening history, were asked about screening intentions with an alternative ending, “…when you are due to screen again?”

Analyses

Independent samples t-tests were used to test differences between treatment and control groups in the primary outcome (i.e., post-intervention CRC numeric lifetime risk perception). Subsequent independent samples t-tests and chi-squared tests of association (for categorical outcomes) were used to test for differences between intervention groups in secondary outcomes (i.e., absolute and relative risk perceptions, behavioral intentions, and breast cancer risk perception at post-intervention). To explore within group differences a series of ad hoc analyses were performed using paired samples t-tests (for continuous outcomes) and McNemar's tests (for categorical outcomes) to detect changes within each group (from pre- to post-intervention).

Results

Sample

Approximately 63,500 panelists were sent survey invitations. Among those solicited for participation, 1,448 panelists clicked on the survey link and consented to participate, including n=671 ineligible panelists per study criteria and an additional 220 per sample quota criteria (i.e., over quotas). Among the remaining 557 respondents, 71 failed to complete the survey (13%) and an additional 67 were removed for failing an attention check (i.e., they did not provide the requested response) (12%). A total of n=419 completed surveys were collected from study eligible participants, resulting in a 24% response rate [46]. Sample characteristics overall and by intervention arm are provided in Table 2.

Primary Outcome

CRC Numeric Lifetime Risk Perception.

No significant differences were observed in any of the post-intervention CRC risk perception measures between the treatment and control groups (Table 3). However, within both groups, the average numeric lifetime risk reported was significantly reduced at post-test (compared to pre-test) ($t(211) = -5.576$, $p < .001$ and $t(206) = -4.848$, $p < .001$ for treatment and control, respectively) and indicated greater accuracy in lifetime risk ($\chi^2(1) = 87.258$, $p < .001$ and $\chi^2(1) = 60.800$, $p < .001$, for treatment and control, respectively).

Secondary Outcomes

CRC Absolute and Relative Risk Perceptions.

The single item indicator of absolute risk of CRC was approaching statistical significance ($t(417) = -1.874$, $p = .06$), with higher risk reported in the treatment group, compared to control (Table 3). Post-hoc tests assessing pre-post change in each group found a significant increase in absolute risk was observed within the treatment group at post-test, compared to pre-test ($t(211) = 2.677$, $p = .008$). Relative risk trended towards a significant decrease within the treatment group ($t(211) = -1.818$, $p = .07$). There were no significant differences in absolute or relative risk perception within the control group.

Behavior Change Intentions.

Post-test intentions to talk to a doctor about CRC screening and intentions for CRC screening, diet and physical activity did not differ significantly by study arm (Table 3). However, behavioral intentions increased for screening, diet, and physical activity among 25-30% of all participants (data not shown). In post-hoc analyses of pre-post change significant increases in

intentions to talk to a doctor about CRC screening ($t(211) = 3.932$, $p < .001$ and $t(206) = 5.148$, $p < .001$ for treatment and control, respectively) as well as CRC screening intentions ($t(211) = 3.961$, $p < .001$ and $t(206) = 4.783$, $p < .001$ for treatment and control, respectively) were identified. Physical activity intentions increased within the control group only ($t(206) = 2.175$, $p = .031$), while diet intentions did not significantly change within either group.

Breast Cancer Risk Perceptions.

There were no significant differences observed in any of the post-intervention breast cancer risk perception measures between the treatment and control groups (Table 3). There were no significant differences within groups in absolute or relative perceptions of breast cancer risk, although a decrease in absolute risk at post-invention was approaching significance within the control group ($t(137) = -1.914$, $p = .06$). Within both the treatment and control groups, the average numeric lifetime risk of breast cancer reported was significantly lower at post-test compared to pre-test ($t(140) = -2.142$, $p = .034$ and $t(137) = -3.111$, $p = .002$, for treatment and control, respectively); accuracy in numeric lifetime risk of breast cancer, however, did not change significantly within either group. Post-hoc McNemar's tests revealed that the overall proportion of individuals who overestimate their lifetime risk of breast cancer significantly decreased, while the overall proportion of individuals who underestimate significantly increased ($\chi^2(1) = 7.902$, $p < .01$ and $\chi^2(1) = 6.919$, $p < .01$, overestimate and underestimate, respectively) [data not shown].

Mammography Screening Intentions.

Post-test mammography screening intentions did not differ significantly by intervention arm. Intentions for mammography screening increased within the control group ($t(137) = 2.166$, $p = .032$). There were no significant changes within the treatment group.

Discussion

Although the hypothesized differences between study arms in post-intervention risk perceptions and behavioral intentions were not supported, several significant within group differences were observed. Specifically, perceived numeric lifetime risk of CRC lowered and seemed to spillover onto female participants' perceived lifetime risk of breast cancer. Results also suggest that cancer risk assessment tools may facilitate behavior change intentions, especially screening intentions. Taken together, findings suggest that risk communication interventions may not need to provide personalized content to improve accuracy of perceived numeric lifetime risk and drive screening intentions among those at average risk of CRC.

The null results between groups on risk perceptions and behavioral intentions do not necessarily contradict the body of literature favoring personalization over non-personalized risk communication [25, 47]. In this study, it is possible that the personalized component of the risk results was overshadowed by the lifetime risk estimate provided to participants. That the overall lifetime risk of participants decreased suggests that the numeric estimate may have been more salient than the information provided on risk factors (regardless of personalization). Therefore, future risk communication research targeting those at average should emphasize that average risk is not zero risk and make messages on the outcomes related to specific lifestyle changes, e.g., the number of CRC cases or CRC deaths that could be prevented, the central focus of the risk

feedback. In order to prevent diminished risk perception among those at average risk, risk communication strategies could also aim to increase awareness of the prevention paradox, the common scenario in which the majority of cases of a disease occur in those at low or moderate risk, while only a same percent occur in those at high risk [48].

Numeric lifetime risk of CRC reported at post-intervention was significantly lower than at pre-intervention in both intervention arms. This reduction reflects greater accuracy in perceived lifetime risk and adds to the body of literature demonstrating improved risk perception accuracy after risk assessment feedback [23-24, 27, 38, 49]. Additional research is needed to identify the cognitive and behavioral implications of altering lifetime risk perception accuracy among average risk individuals. In particular, future studies should evaluate whether increased risk perception accuracy among average risk individuals is beneficial or detrimental (i.e., leads to a false sense of security and impedes adoption of health behaviors).

Women's' perceived lifetime risk of breast cancer also significantly decreased at post-intervention (compared to pre-intervention), regardless of study arm. These unexpected changes in women's perceived lifetime risk of breast cancer following CRC risk feedback may represent an unintended, and potentially adverse, consequence of providing cancer type-specific assessment results. Future research is warranted to replicate these results. In the meantime, cancer prevention and risk communication professionals should be cognizant of the potential for such spillover effects.

On the other hand, CRC screening intentions as well as intentions to talk to a doctor about CRC screening significantly increased at post-intervention (compared to pre-intervention), again regardless of group. This finding suggests that cancer risk assessments may be useful in

promoting screening behavioral intentions among average risk individuals regardless of whether the content is personalized. Within the control group, mammography screening intentions also increased at post-intervention. This is somewhat surprising given both perceived lifetime and absolute risk decreased in this group (although the latter did not reach statistical significance). This result may indicate that generic feedback on specific risk factors (including screening behavior) is more likely to produce spillover intentions on other types of cancer. Findings such as these highlight the importance of explicitly test for spillover effects as interventions that can successfully change multiple behaviors are likely to be more efficient than those targeting one behaviors at a time.

While results related to screening intentions are encouraging, there were limited effects observed on diet and physical activity intentions. The null results related to diet intentions is particularly worrisome given that dietary habits are strongly associated with CRC risk and an unhealthy diet was the most prevalent risk factor identified in this sample. It is possible that screening is perceived differently, i.e., a "one and done" behavior to reduce risk, as opposed to an ongoing, daily change in lifestyle. Alternatively, screening was the only negatively-framed message; therefore, behavioral intentions of average risk individuals may be influenced more by negatively-framed prevention messages, although this would contrast prior work supporting an advantage of gain-framed messages on preventive behaviors intentions [41, 50]. Moreover, the positive/negative framing of messages only applied to the behaviors regarded as risk factors. The presence or absence of risk factors (as defined by participant reported engagement in health behaviors) produced variation within the treatment arm personalized messages. Potential differences in outcomes associated with the varying message combinations were not evaluated in

the present study. It is possible that these differences within the treatment arm muddied our ability to detect the effects of personalization. Future research should examine specific forms of personalization more closely within defined risk groups. These results underscore the need for future research on the role risk information plays in promoting behavior change intentions, and in addition, the relative difficulty researchers face in "moving the needle" on lifestyle modifications among individuals without a family history of cancer.

Finally, the null findings between trial arms may be partially explained by the average risk (and thus by definition low risk) status of the study sample. Participants were purposefully provided with a low numerical risk estimate of less than 5% which may have been judged of insufficient magnitude to heighten perceptions of risk. This supposition is bolstered by the fact that perceived numeric lifetime risk of CRC decreased in both groups post-intervention. If this explanation were true, it would provide a potential caveat to prior research suggesting that personalized risk feedback is more successful in motivating changes in lifestyle behaviors [51]. However, the single item used to indicate absolute risk significantly increased from pre- to post-intervention within the treatment group and was approaching statistical significance ($t(417) = -1.874$, $p = .06$), with higher risk reported in the treatment group, compared to control (as hypothesized). This result offers some evidence pointing to a potentially beneficial role of personalized information in promoting change (via increased non-numeric perception of risk), even when provided in combination with average and relatively low estimates of lifetime risk.

Strengths and Limitations

A primary limitation of this study was the relative similarity between the treatment and control arms. That all participants received a numeric estimate of lifetime risk and information

on risk factors may explain the limited changes in the primary outcome (i.e., risk perception). It is also possible that the degree of personalization within the treatment arm was not enough. The information provided on risk factors could have been further personalized based on participant age and race/ethnicity. Enhanced personalization that reinforces the threat of CRC (despite being at average risk), combined with clearer differences between the personalized and non-personalized arms, may be necessary to isolate the effects of personalization when communicating information about risk factors to those at average risk.

In addition, responses from this internet panel sample may not generalize to populations that do not engage in online research. Nor do survey responses regarding behavioral intent necessarily translate actual behavioral change. The public use of risk assessment tools may be influenced by different individual characteristics such as motivations, interests, and readiness to change. Finally, the lifetime risk estimates provided in this study were based on the average combined lifetime risk of men and women in the United States and were not personalized for each respondent. Although the actual estimated range of lifetime risk in an average risk sample would be relatively small, providing individualized risk estimates may yield different results. Therefore, it may be beneficial to repeat this study with more precise estimates of lifetime risk.

The limitations of this study are balanced by several strengths. First, the sample is economically and racially diverse which enhances the ability to generalize findings to such populations, an uncommon trait of internet samples [52]. In addition, the sample consists of individuals with average risk for CRC, a relatively understudied, yet critical population to study cancer risk assessment and preventive behaviors, since the majority of CRC will occur among

individuals without a family history [53]. Finally, the internet survey did not allow respondents to skip questions and therefore, there was no need to statistically account for missing data.

Conclusion

Taken together, results here highlight the complexity of cancer risk perceptions and suggest that cancer risk assessment tools may alter risk perceptions and facilitate behavior change intentions, especially screening intentions, among an average risk population. Our findings shed new light on the potential utility of cancer risk assessment tools as vehicles to improve the accuracy of individuals' cancer risk perceptions while promoting risk-reducing behaviors.

Table 1. Treatment Group Messages

Behavior	Protective Message	Risk Message
Screening	You've had one of the colon cancer screening tests recently.	**Get screened for colon cancer regularly.** If you do not get screened doctors will not be able to find and remove precancerous polyps before they turn into cancer. So, talk to your doctor about getting screened. Regular screening is the single best way to lower your colon cancer risk.
Physical Activity	You are physically active.	**Increase your physical activity.** Work towards at least 30 minutes of physical activity a day. Being physically active can lower your colon cancer risk by as much as half.
Diet	You eat a diet high in vegetables.	**Improve your diet.** Strive to eat more vegetables and less than 3 servings of red meat a week. A diet high in vegetables may help reduce your risk of colon cancer.

Table 2. Sample Characteristics Overall and by Intervention Arm (N=419)

Variable	Overall	Control (n=207)	Treatment (n=212)
Demographic Characteristics			
Mean Age (sd)	58.5 (6.3)	58.7 (6.3)	58.3 (6.2)
Female Gender	279 (66.6)	138 (66.7)	141 (66.5)
Race			
White	140 (33.4)	73 (35.3)	67 (31.6)
Black	140 (33.4)	64 (30.9)	76 (35.8)
Hispanic	139 (33.2)	70 (33.8)	69 (32.5)
Currently Married[a]	203 (48.4)	106 (51.2)	97 (45.8)
Income			
<20k	94 (22.4)	47 (22.7)	47 (22.2)
20-49k	145 (34.6)	61 (29.5)	84 (39.6)
50-74k	90 (21.5)	50 (24.2)	40 (18.9)
75-99k	46 (11.0)	24 (11.6)	22 (10.4)
≥100k	44 (10.5)	25 (12.1)	19 (9.0)
College Graduate	203 (48.4)	105 (50.7)	98 (46.2)
Currently Employed[b]	173 (41.3)	88 (42.5)	85 (40.1)
Insured	368 (87.8)	182 (87.9)	186 (87.7)
Colorectal Cancer Risk Factors/Screening			
Mean Targeted Risk Factors/Screening (sd) (0-3)[c]	1.8 (0.8)	1.8 (0.8)	1.7 (0.8)
Colorectal Cancer Screening[d]	209 (49.9)	104 (50.2)	105 (49.5)
Physical Activity[e]	182 (43.4)	89 (43.0)	93 (43.9)
Inadequate Vegetable Consumption[e]	348 (83.1)	176 (85.0)	172 (81.1)

Note. Values represent total number (column percentage) unless otherwise stated.

[a] Currently married or living with significant other

[b] Currently employed full-time or part-time

[c] Includes CRC screening, physical activity and diet risk factors

[d] Not up-to-date per guidelines

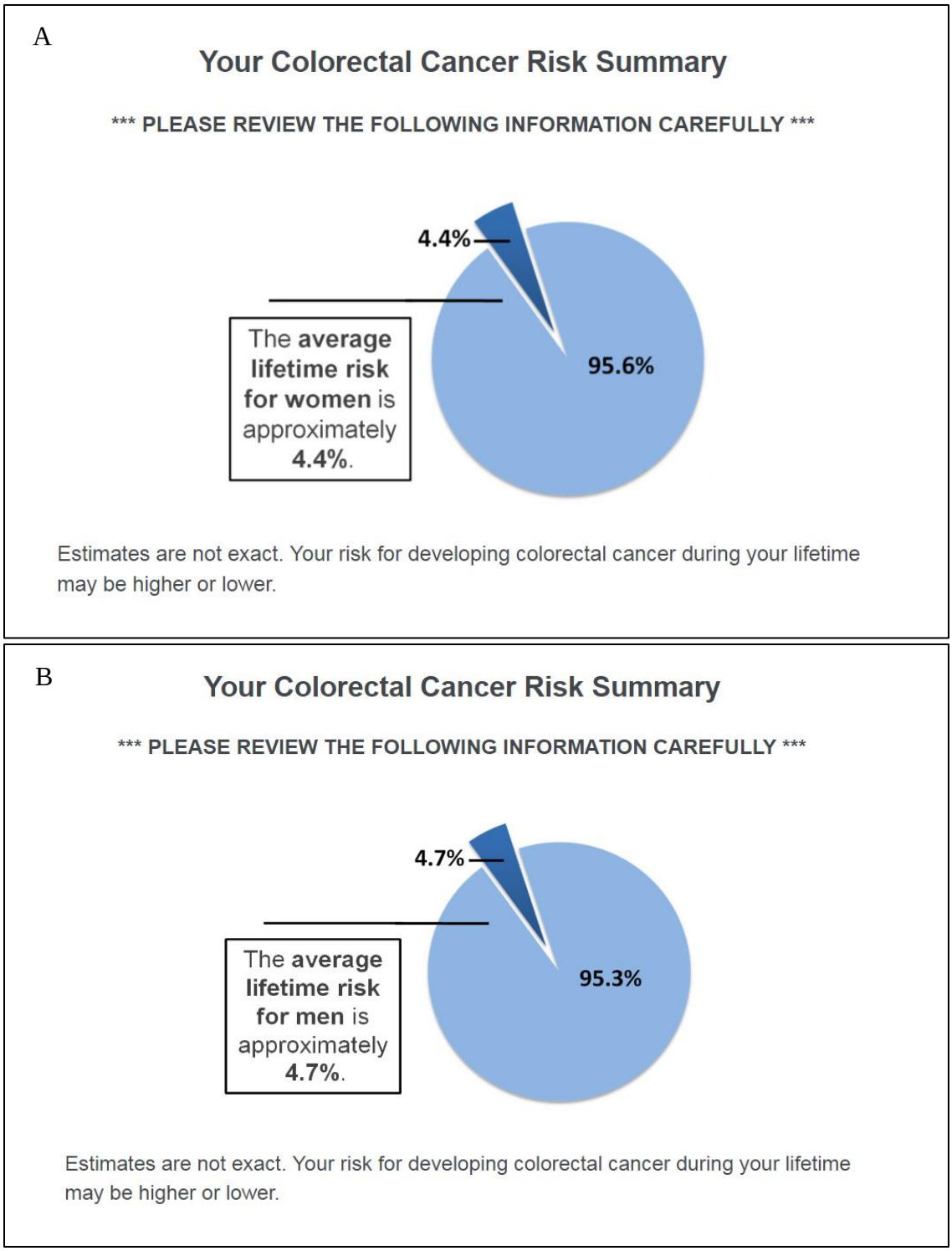
[e] Inadequate per guidelines

Table 3. Risk Perceptions and Behavioral Intentions by Group at Pre-Intervention and Post-Intervention (N=419)

Variable	*Post-Intervention*			*Pre-Intervention*		*Within Groups*[3]	
	Control (n=207) *n (%)*	Treatment (n=212) *n (%)*	Between Groups[1,2] *p*	Control (n=207) *n (%)*	Treatment (n=212) *n (%)*	Control *p*	Treatment *p*
Colorectal Cancer Risk Perceptions							
Perceived Lifetime Risk							
Mean Percentage (sd) (0-100%)	11.0 (16.6)	11.0 (16.0)	0.999	18.9 (21.1)	17.8 (20.9)	0.000	0.000
Accurate Lifetime Risk (N (%))[c]	92 (44.4)	103 (48.6)	0.396	15 (7.2)	10 (4.7)	0.000	0.000
Perceived Absolute Risk							
Mean Absolute Risk (sd)[a]	2.2 (0.9)	2.4 (1.0)	0.062	2.1 (0.9)	2.2 (1.0)	0.170	0.008
Perceived Relative Risk							
Mean Relative Risk (sd)[b]	2.3 (0.9)	2.2 (1.0)	0.378	2.3 (1.0)	2.3 (1.1)	0.93	0.071
Behavioral Intentions							
Colorectal Cancer Screening							
Mean Screening Intention (sd)[e]	3.0 (1.4)	3.2 (1.5)	0.278	2.7 (1.4)	2.9 (1.4)	0.000	0.000
Mean Intention to Talk to Doctor (sd)[e]	2.9 (1.3)	2.9 (1.4)	0.844	2.6 (1.3)	2.7 (1.3)	0.000	0.000
Physical Activity							
Mean Physical Activity Intention (sd)[e]	3.2 (1.1)	3.2 (1.2)	0.867	3.1 (1.2)	3.1 (1.2)	0.031	0.180
Diet							
Mean Diet Intention (sd)[e]	3.3 (1.2)	3.3 (1.2)	0.917	3.2 (1.2)	3.2 (1.1)	0.175	0.471
Breast Cancer Risk Perceptions and Screening Intentions (n=279 women)							
Perceived Absolute Risk							
Mean Absolute Risk (sd)[a]	2.4 (1.0)	2.5 (1.0)	0.492	2.5 (1.0)	2.4 (1.1)	0.058	0.154
Perceived Relative Risk							
Mean Relative Risk (sd)[b]	2.6 (1.1)	2.5 (1.0)	0.474	2.6 (1.0)	2.5 (1.1)	0.433	0.347
Perceived Lifetime Risk							
Mean Percentage (sd) (0-100%)	22.1 (23.1)	20.6 (24.1)	0.606	26.2 (24.4)	22.5 (24.0)	0.002	0.034
Accurate Lifetime Risk (N (%))[d]	12 (11.2)	14 (12.2)	0.824	15 (14.0)	15 (13.0)	0.629	1.000
Mammography Screening							
Mean Mammography Intention (sd)[e]	3.9 (1.4)	3.8 (1.5)	0.754	3.7 (1.4)	3.7 (1.4)	0.032	0.338

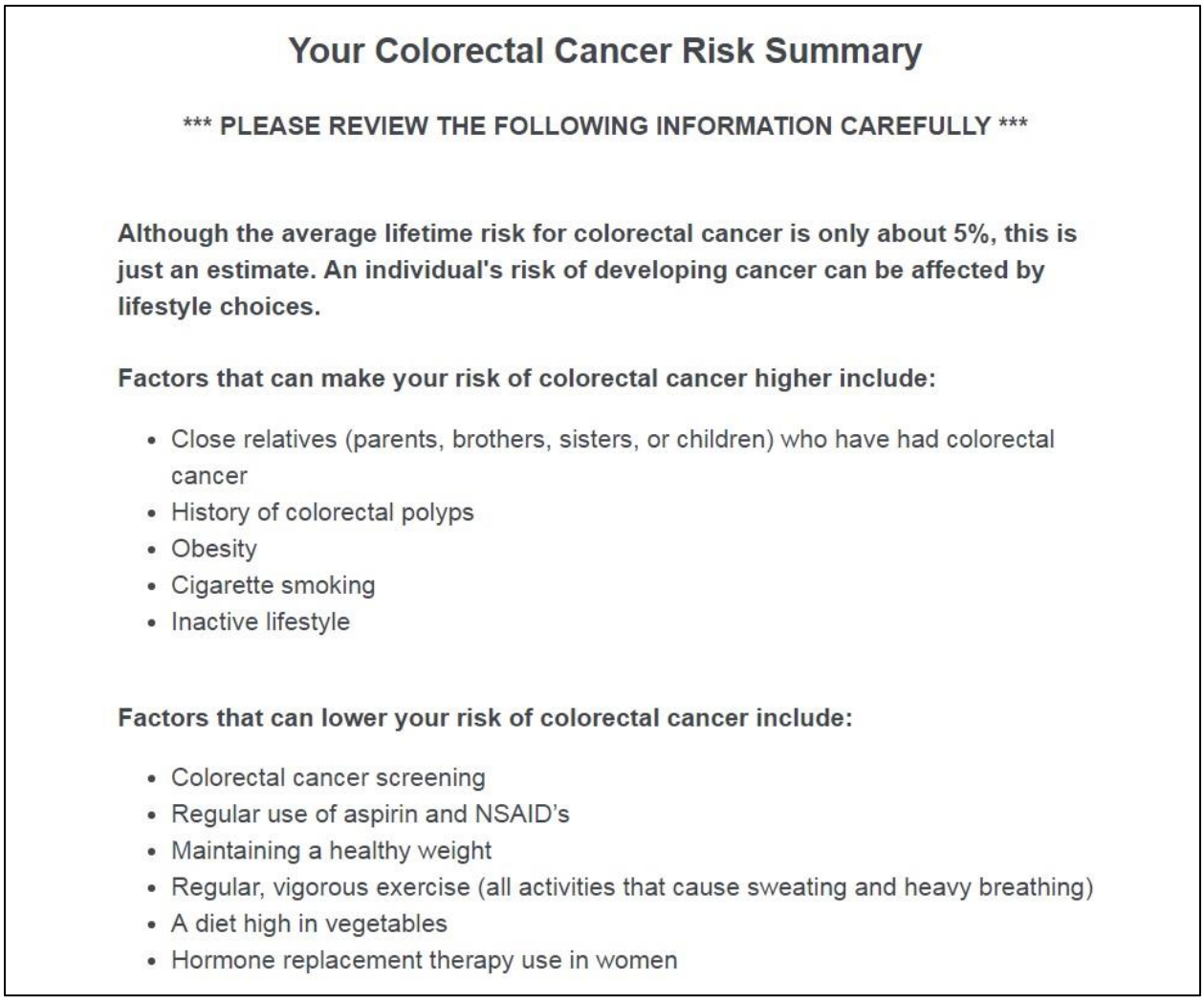
Note.
[1] Between groups: post-test only comparison between treatment vs. control (independent samples t-tests and chi-squared test of association)
[2] Analyses controlling for pre-test values were performed and did not produce different outcomes.
[3] Within groups: pre-test vs. post-test (paired samples t-tests and McNemar's tests) within each group (control and treatment)
[a] Item measured on a 5 point Likert scale, Very Unlikely (1) to Very Likely (5)
[b] Item measured on a 5 point Likert scale, Much Lower (1) to Much Higher (5)
[c] Between 4-5% coded as accurate
[d] Between 10-15% coded as accurate
[e] Item measured on a 5 point Likert scale, Not At All (1) to Extremely (5)

Figure 1. Lifetime Risk for Colorectal Cancer



Note. Figure 1 depicts lifetime risk for men (A) and women (B).

Figure 2. Control Group Risk Factory Message



Your Colorectal Cancer Risk Summary

***** PLEASE REVIEW THE FOLLOWING INFORMATION CAREFULLY *****

Although the average lifetime risk for colorectal cancer is only about 5%, this is just an estimate. An individual's risk of developing cancer can be affected by lifestyle choices.

Factors that can make your risk of colorectal cancer higher include:

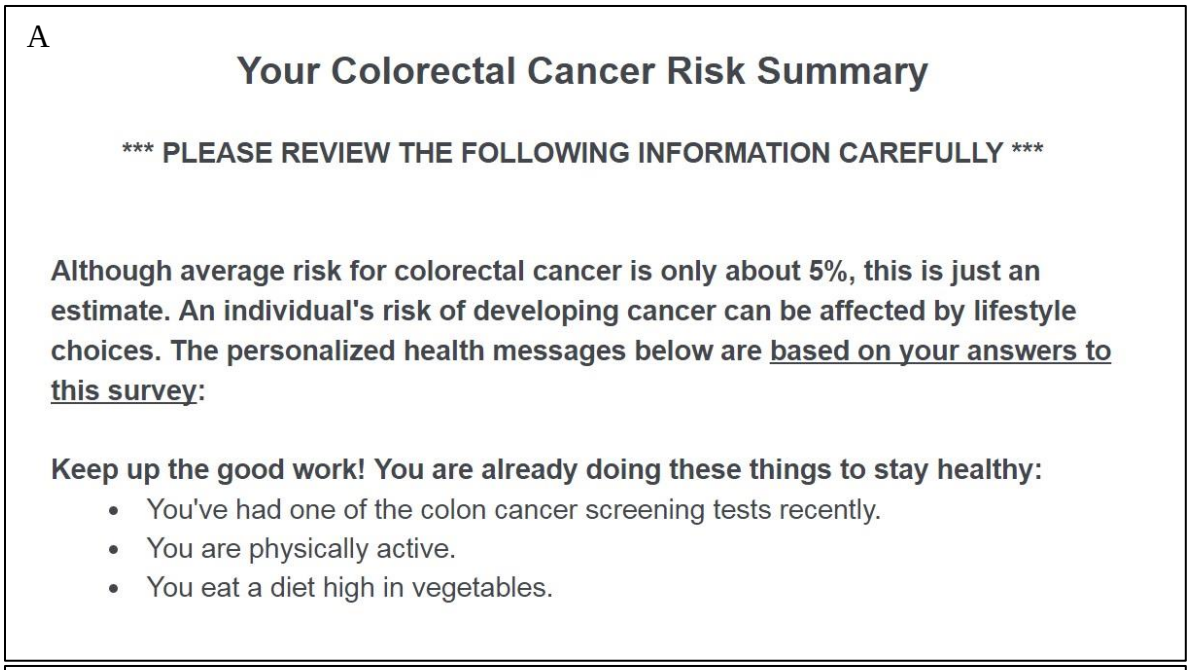
- Close relatives (parents, brothers, sisters, or children) who have had colorectal cancer
- History of colorectal polyps
- Obesity
- Cigarette smoking
- Inactive lifestyle

Factors that can lower your risk of colorectal cancer include:

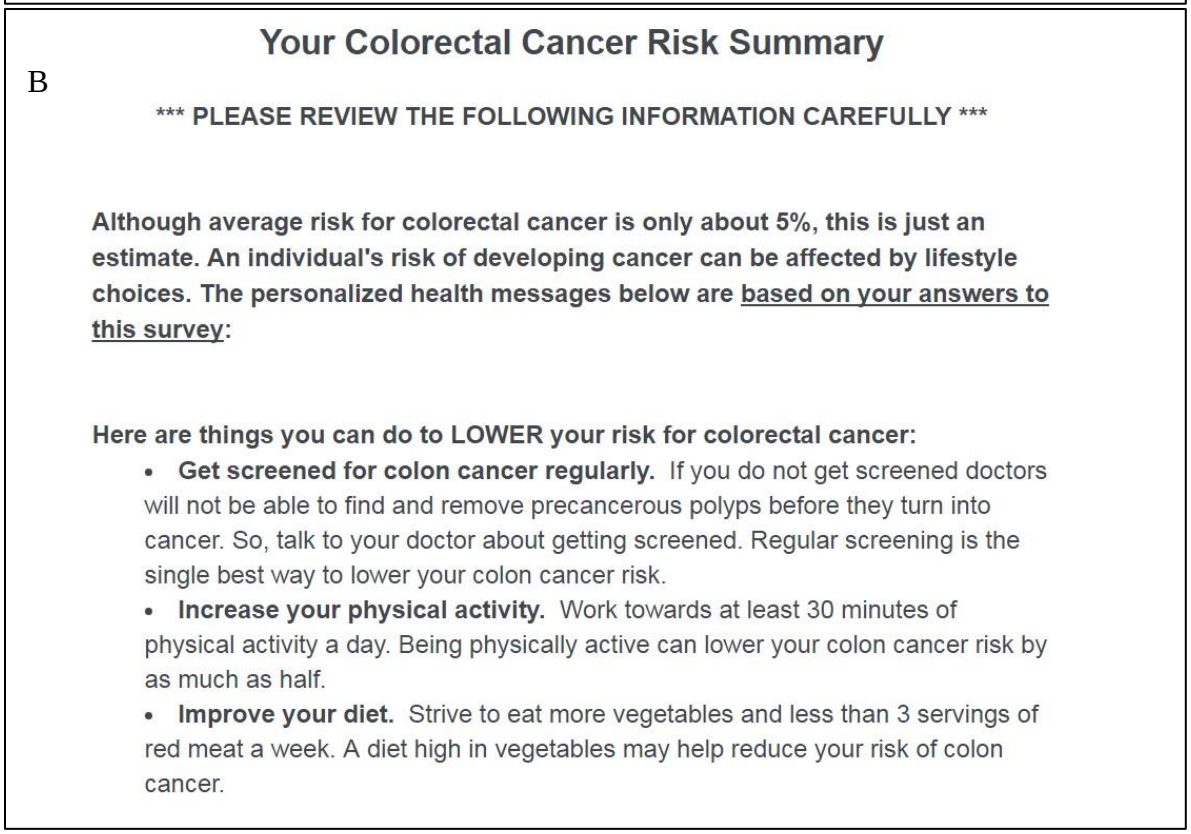
- Colorectal cancer screening
- Regular use of aspirin and NSAID's
- Maintaining a healthy weight
- Regular, vigorous exercise (all activities that cause sweating and heavy breathing)
- A diet high in vegetables
- Hormone replacement therapy use in women

Figure 3. Treatment Group Risk Factor Messages

A



B



Note. Figure 3 depicts risk factors framed as risk (A) and protective (B) factors.

Footnotes

[1] Qualtrics outsourced recruitment to partner companies with established panels.

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CHAPTER 3

Paper Two

POST RISK ASSESSMENT COLORECTAL CANCER LIFETIME RISK ACCURACY AND BEHAVIOR CHANGE INTENTIONS

Abstract

Background

Accurately gauging risk may be an important factor in promoting preventive health behaviors. Cancer risk assessment can improve risk perception accuracy, but little is known about how improved accuracy affects health behavior change intentions within the average risk population.

Purpose

The purpose of this study was to examine accuracy of perceived lifetime risk of CRC prior to and immediately following receipt of CRA feedback within a sample of average risk adults. We also assessed whether improvement in perceived lifetime risk accuracy was associated with changes in behavior change intentions for physical activity, diet and attending CRC screening.

Methods

Data were collected as part of a pre-post parallel design randomized controlled trial examining the impact of CRC cancer risk assessment (CRA) feedback. Adults aged 50-75 years with no personal or family history of CRC (N=419) were enrolled in the parent study. Participants' colorectal cancer risk perceptions and behavioral intentions were ascertained immediately before and after risk assessment administration.

Results

Accuracy of perceived lifetime risk significantly improved after CRA feedback. Those who were White (compared to Black or Hispanic), married, college educated (compared to college graduates) and had higher numeracy were more likely to report accurate lifetime risk post-CRA. No differences in behavioral intentions were reported between those with improved accuracy and those who remained inaccurate post-CRA.

Conclusion

CRAs can significantly improve perceived lifetime risk accuracy among those at average risk. Although improved accuracy was not associated with increased behavioral change intentions, it is reassuring that improved accuracy (via a decrease in perceived risk) did not inhibit (reduce) intentions for health behaviors.

Background

Although CRC incidence is relatively low within the U.S. population, it is not a negligible threat and should not be dismissed. Colorectal cancer (CRC) is the third most commonly diagnosed cancer among men and women in the United States (US) and the second leading cause of cancer deaths overall [1]. Approximately 50,000 deaths were estimated to occur from the disease in 2017 [1]. CRC risk can be reduced through regular screening and lifestyle modification, such as improving diet and physical activity [2-4]. In fact, it has been estimated that as much as 70% of CRC cases could be prevented through lifestyle modification and widespread screening [5]. However, roughly 32 million Americans believe nothing can be done to reduce an individual's cancer risk [6]. Informing the public on disease risk and the modifiable risk factors for CRC may be an important first step in motivating changes in lifestyle and other risk-reducing behaviors, such as cancer screenings. Numerous theories of health behavior provide rationale for using risk information to promote cancer prevention, postulating that increasing an individual's perception of risk will lead to behavioral changes to reduce risk [7-9].

Cancer risk prediction models and assessment tools, hereafter referred to as cancer risk assessments (CRAs), have been developed to convey risk information and inform prevention strategies. Although CRAs are typically used for those at increased risk in the clinical setting, CRAs have the potential to inform prevention strategies across the spectrum of cancer risk [10]. A systematic review of trials using CRAs in primary care (n=11) suggests potentially beneficial effects of risk assessment feedback in accuracy of risk perceptions and screening intentions, without increasing cancer-related anxiety [11]. However, the relatively small evidence base in this review was heterogeneous in terms of cancer and intervention type and included studies

targeting groups with existing concerns about their risk due to family history. Within CRC specifically, population level approaches to risk reduction would yield highest benefits, since approximately 70% of CRC cases occur in patients with no family history of the disease (i.e., "average risk" individuals) [12]. However, little is known about the application of CRAs for population approaches to cancer prevention (i.e., targeting the whole population, not only those at high risk), or the psychosocial and behavioral impact of CRA feedback on average risk individuals, who represent the majority of colorectal cancer cases.

Despite the threat, perceptions of CRC risk are low in the general population [13-15] and often incorrectly estimated in average risk research samples [16-17]. Accurately gauging risk may be an important factor in promoting preventive health behaviors within the average risk population who may not receive as compelling of behavioral recommendations as those identified as high risk. Previous research has suggested that providing personalized CRC absolute and relative risk estimates improves the accuracy of these risk perceptions among older adults with no personal history of cancer [16-17]. Categorical relative risk estimates (e.g., "average risk") and absolute risk estimates (e.g., "x chances in 1000") over a 20-year period were provided in these studies. However, an estimate of the accumulated risk over a lifetime may provide more valuable information to adults with average CRC risk. Specifically, being informed that your lifetime risk of developing CRC is between 4-5%, may elicit different risk perceptions and behavior change intentions than other risk presentation formats. It is unclear whether the provision of CRA results will improve lifetime risk perceptions among individuals with no personal or family history of CRC and whether improved accuracy of lifetime risk is beneficial among those at average risk. Moreover, it is not known if improved accuracy of lifetime risk

increases uptake of preventive health behaviors or alternatively could contribute to ambivalence or discourage the adoption of lifestyle change behaviors.

The present research study examined individuals' accuracy of perceived lifetime risk of CRC prior to and immediately following receipt of CRA feedback within a sample of average risk adults. The aims of this study were to: characterize perceived lifetime risk prior to CRA feedback; examine predictors of baseline perceived lifetime risk accuracy and identify predictors of improved risk perceptions among those who were inaccurate at baseline. A final question assessed whether improvement in perceived lifetime risk accuracy was associated with changes in behavior change intentions for physical activity, diet and attending CRC screening.

Methods

Study Design

Data for this study was collected as part of an IRB approved randomized controlled trial examining the impact of CRA feedback on perceived risk and behavioral intentions using a pre-post parallel trial design.[1] As part of that parent study the participants were randomized to one of two arms receiving colorectal cancer risk results including a population-based estimate of average lifetime risk according to gender (4.7% for men and 4.4% for women) and information about CRC risk factors that was either invariant and non-personalized (arm one) or personalized recommendations based on respondent reported risk factors (arm two). No effects for intervention arm on risk perceptions or behavioral intentions were found in the parent study. For the purposes of this study, intervention arm was used as a covariate in regression analyses.

Sample and Survey Administration

The target population for the study was adults, aged 50-75 years, with no personal or family history of colorectal cancer, or known predisposition or condition (e.g., inflammatory bowel disease, polyps or a hereditary syndrome such as familial adenomatous polyposis (FAP) or hereditary nonpolyposis colon cancer (HNPCC), also known as Lynch Syndrome). The sample was also limited to English-speaking residents of the contiguous United States.

The study was conducted using Qualtrics, a leading online survey research company, in June 2017. Participants were recruited from existing participant panels.[2] Panelists were invited to participate using a double opt-in process. Potential participants received an email invitation informing them about the study and providing a link to the study consent form and survey. Quota sampling was used to obtain a sample balanced by race/ethnic identity (White, Black/African American and Hispanic/Latino/Spanish origin) and representative ranges of annual household incomes. Participants received the equivalent of approximately $5.00 remuneration for participation. Survey items measured numeracy, socio-demographic characteristics (e.g., age, gender, race, education, marital status, and employment status), and baseline health behaviors (e.g., physical activity, vegetable consumption, and CRC screening), as well as risk perception.

Outcome Measures

Lifetime Risk Accuracy.

Perceived lifetime risk was assessed at pre- and post-CRA with a single item, “On a scale from 0 to 100 %, how would you rate the probability that you will develop colorectal cancer in the future?” with an open-response of 0-100%. A dichotomous measure of lifetime risk accuracy was created that defined ‘accurate’ as a response between four and five percent, according to

statistics from the American Cancer Society [18]. A binary variable was also created to indicate those with improved lifetime risk accuracy at post-CRA (i.e., those with an inaccurate perception at pre-CRA and an accurate perception at post-CRA).

Behavioral Intentions.

Behavior change intentions related to colorectal cancer screening, diet and physical activity were measured at pre- and post-CRA. Based on previous CRC screening research [19], respondents were asked a single item adapted for each behavior, "How likely are you to [get screened for colorectal cancer, improve your diet, and increase your physical activity] in the next 6 months?" with a five-point Likert response scale of "not at all to "extremely." Participants classified as up-to-date on screening (per self-reported screening behavior) were asked about screening intentions using an alternative ending, "…when you are due to screen again?"

Analyses

Paired samples McNemar's tests were used to assess differences in the proportion of participants with an inaccurate lifetime risk perception at pre- and post-CRA. Adjusted logistic regression models were estimated to assess (1) predictors of pre-CRA lifetime risk accuracy and (2) predictors of post-CRA improvement in lifetime risk accuracy among those who were inaccurate at pre-CRA while controlling for pre-CRA accuracy level (i.e., overestimate or underestimate). Those with an accurate perception of lifetime risk at pre-CRA were excluded from the latter regression analysis. Behavioral intentions were assessed between those with improved lifetime risk accuracy and those who remained inaccurate at post-CRA using five-point Likert scales. When regarded as continuous outcomes, independent samples t-tests were used to test for differences in behavioral intentions. Differences in the proportion of participants that

increased behavioral intentions from pre- to post-CRA were assessed using chi-squared tests of association. Analyses were performed using SPSS version 24.

Results

Sample Characteristics

Among the 1,606 panelists that initiated participation (i.e., clicked on the survey link and completed the consent page), 158 declined, 671 did not meet study eligibility criteria and an additional 220 screened out due to quota sampling. Seventy-one respondents did not complete the survey and an additional 67 were removed from the study for failing an attention check (i.e., one of three survey items that required specific responses). A total of n=419 eligible participants were included in this analysis.

Participants were 58.5 years old on average (sd=6.3). Sixty-seven percent of the sample were female (n=279). As designed, the sample included equal proportions of White, Black, and Hispanic participants (33% each). Almost half of respondents were married (48%) and college educated (48%). Less than half were employed (41%) and 43% reported an annual household income of $50,000 or higher. On average, respondents correctly answered 2.4 (sd=1.2) of the five numeracy questions accurately. Sample characteristics are presented in Table 1.

Pre-CRA Lifetime Risk

The average perceived lifetime risk of CRC reported at baseline (pre-CRA) was 18% (sd=21.0); responses ranged between 0 and 100%. As shown in Table 2, few participants (n=25) had an accurate perception of their lifetime risk of CRC. The majority of participants

overestimated (57%) or underestimated (38%) their lifetime risk prior to receiving CRA feedback.

Predictors of Pre-CRA Lifetime Risk Accuracy

Results from an adjusted logistic regression indicated that those currently employed were less likely to report lifetime risk accurately at baseline (see Table 3). No other factors were associated with baseline lifetime risk accuracy in this model controlling for numeracy and study arm.

Predictors of Improved Post-CRA Lifetime Risk Accuracy

The overall average perceived lifetime risk reported post-CRA was 11% (sd=16.3); responses ranged between 0 and 95%. As shown in Table 2, n=195 participants had an accurate perception of their lifetime risk for colorectal cancer post-CRA (47%). The proportion of participants with an accurate perception of lifetime risk significantly increased from pre to post ($\chi^2(1) = 148.755$, $p < .001$). Concurrently, the proportions of participants underestimating and overestimating their lifetime risk significantly decreased from pre- to post-CRA ($\chi^2(1) = 33.307$, $p < .001$ and $\chi^2(1) = 73.333$, $p < .001$ for underestimating and overestimating, respectively).

Among the n=394 participants with an inaccurate perception of lifetime risk at pre-CRA, n=181 improved their perception of lifetime risk from inaccurate to accurate at post-CRA ($\chi^2(1) = 179.006$, $p < .001$). Table 4 presents results of the logistic regression analysis testing the role of participant characteristics, controlling for numeracy, pre-CRA accuracy level, and study arm, on improved accuracy of lifetime risk at post-CRA. Whites (compared to Blacks and Hispanics), those who were married, those with some college education (compared to college graduates) and higher numeracy had a higher likelihood of reporting an accurate lifetime risk post-CRA. The

likelihood of lifetime risk accuracy at post-CRA was not statistically different between those with a high school degree or less education and those with a college degree.

Post-CRA Improved Lifetime Risk Accuracy and Behavioral Intentions

The behavioral intentions of participants who improved lifetime risk accuracy from pre to post were not significantly different from those that remained inaccurate at post-CRA. As shown in Table 5, there were no differences in the mean behavioral intentions for screening, diet and physical activity at post-CRA between those who improved accuracy and those who remained inaccurate (left side of table). Similarly, no differences were observed in the proportion of participants that increased their behavior change intentions for any behavior from pre to post between those with an improved perception of lifetime risk and those who remained inaccurate at post-CRA (right side of Table 5).

Discussion

In order to understand who stands to benefit from receiving cancer risk information, this study identified predictors of CRC perceived lifetime risk accuracy prior to and following CRA feedback. The analysis of predictors of post-CRA perceived lifetime risk accuracy revealed higher likelihood of accuracy among Whites (compared to Blacks and Hispanics), the married, those with some college (compared to college graduates) and higher numeracy. One of the more interesting findings is that instead of revealing who is most likely to benefit from CRA feedback, results implied meaningful information about who was less likely to benefit. In particular, we found lower post-CRA accuracy was more likely among minorities and individuals with low numeracy. Higher proportions of Blacks and Hispanics continued to underestimate (29% and 24%, respectively, compared to 17% Whites) and overestimate (37% and 34%, respectively,

compared to 21% Whites) their risk post-CRA. Understanding what is driving the differences within these traditionally underserved subgroups of the population could help inform the development of more effective risk communication strategies. Previous research using national data has observed lower cancer risk perceptions among Blacks and Hispanics compared to Whites [20-22]. At least one study has speculated that racial differences in awareness of family history of cancer may account for observed differences in cancer risk perception [21]. However, our results suggest that racial differences in risk perception persist within a sample consisting entirely of individuals reporting no known family history of CRC. Risk perceptions may also be influenced by medical mistrust and different health attitudes and perceptions among minority groups [23]. The finding that those who had low numeracy scores are less likely to have accurate lifetime risk perception post-CRA is not surprising since previous research has supported an association between numeracy and the perception of health risks [24]. Since a basic numeric proficiency is required to understand cancer risk information [25], our results suggest that communicating risk information that accommodates varying numeracy levels may be important. As long as disparities in CRC incidence and mortality persist, greater attention is warranted to understand whether and how risk perception inaccuracies contribute to these disparities and how best to address these perceptions. [26].

Results of the analysis of predictors of pre-CRA accuracy indicated that currently employed individuals were significantly less likely to have perceived lifetime risk accuracy, compared to those not currently employed. Although this is an unexpected finding it should be interpreted with caution as only 6% of participants accurately reported lifetime risk of CRC at pre-CRA. A larger sample size may be necessary to establish a better understanding of baseline predictors of

lifetime risk accuracy and subsequently, to characterize those who may be most in need of CRA feedback. Moreover, the proportion of employed adults in this sample is somewhat lower than the proportion of employed adults in the U.S. population of adults aged 50-75 years (41% versus 53%, respectively) [27]. Future research is needed to determine how generalizable internet samples are to the population and to other research samples using different sampling strategies, especially when targeting older adults.

An examination of improvements in lifetime risk perception and behavior change intentions revealed no differences in intentions between those with an accurate versus inaccurate lifetime risk perception at post-CRA. It may be that accuracy of lifetime risk perception is not a significant precursor to the adoption of preventive behaviors or, in this case, it may be that having accurate knowledge of the *average* lifetime risk of CRC is not a salient catalyst to produce health behavior change intentions. Considering that knowledge alone is considered necessary but not sufficient to change behavior, additional studies should focus on developing effective messages in the context of CRA to emphasize not only that those at average risk are still *at risk* but also to encourage health behavior change to reduce risk and prevent disease. For example, rather than emphasizing the accuracy of lifetime risk, which at 5% is rather low, public health messaging can focus on the benefits of prevention and early detection behaviors in terms of the proportion of cases prevented.

Strengths and Limitations

By exploring whether risk perception accuracy was associated with behavior change intentions, this study helped fill a gap in the existing literature base. Although improved accuracy was not associated with positive behavioral intentions as expected, that intentions did not

decrease when perceived risk lowered provides novel information. Results also point to future directions for research. The items assessing lifestyle behavioral intentions were possibly phrased too broadly. Asking specifically about intentions to increase intake of fruits and vegetables or reduce red meat consumption, for example, may have produced different outcomes than asking about intentions to "improve your diet." Another potential limitation of the present research is that we did not fully capitalize on having a racially/ethnically diverse sample. Providing culturally-sensitive personalized messages by racial/ethnic group could better promote behavior change intentions and therefore, should be incorporated in future studies examining CRA feedback.

Conclusion

Very few participants had an accurate understanding of lifetime risk for CRC at baseline. Although the percentage of participants with accurate lifetime risk significantly increased following CRA feedback, more than half of participants remained inaccurate. This demonstrated lack of awareness of CRC risk is concerning. Minorities and those with low numeracy were more likely to report inaccurate perceptions post-CRA, highlighting well-documented disparities in risk perception and the comprehension of complex, numerical information. Although accuracy at post-CRA was not associated with increased behavioral intentions, it is reassuring that improved accuracy (often via a decrease in perceived risk) was not associated with lower health behavior intentions. In conclusion, accuracy of perceived lifetime risk is just one facet of potential outcomes to examine following CRA. Additional research is needed to improve post-CRA accuracy and understanding among minority and low numeracy groups, including testing risk communication strategies conveying risk information tailored to an individual's race and

numeracy. Future public health efforts should continue to explore the potential utility of CRAs to promote cancer prevention in both high and average risk groups.

Table 1. Sample Characteristics (N=419)

Variable	n (%)
Mean Age (sd)	58.5 (6.3)
Female Gender	279 (66.6)
Race	
White	140 (33.4)
Black	140 (33.4)
Hispanic	139 (33.2)
Currently Married[a]	203 (48.4)
Income	
<20k	94 (22.4)
20-49k	145 (34.6)
50-74k	90 (21.5)
75-99k	46 (11.0)
≥100k	44 (10.5)
College Graduate	203 (48.4)
Currently Employed[b]	173 (41.3)
Mean Numeracy (sd) (0-5)	2.4 (1.2)

Note.

[a] Currently married or living with significant other

[b] Currently employed full-time or part-time

Table 2. Accuracy Level of Perceived Lifetime Risk of CRC at Pre- and Post-CRA (N=419)

Accuracy Level	Pre-CRA *(n (%))*	Post-CRA *(n (%))*	*p*
Underestimated	157 (37.5)	98 (23.4)	<0.001
Accurately Estimated	25 (6.0)	195 (46.5)	<0.001
Overestimated	237 (56.6)	126 (30.0)	<0.001

Table 3. Adjusted Logistic Regression: Pre-CRA Perceived Lifetime Risk Accuracy (N=419)

	Pre-CRA Accurate Lifetime Risk Perception						
						95% CI for EXP(B)	
Variable	*B*	*SE B*	*Wald*	*df*	*Exp(B)*	*Lower*	*Upper*
Numeracy	0.151	0.162	0.864	1	1.163	0.846	1.598
Age (years)	-0.002	0.035	0.004	1	0.998	0.932	1.068
Male Gender (ref: Female)	-0.239	0.471	0.258	1	0.787	0.313	1.982
Race (ref: White)							
Black	-0.289	0.560	0.266	1	0.749	0.250	2.244
Hispanic	-0.001	0.525	0.000	1	0.999	0.357	2.797
Married (ref: Not Married)	0.186	0.436	0.182	1	1.205	0.512	2.835
Education (ref: College Graduate)							
High School Degree or Less	-1.146	0.693	2.738	1	0.318	0.082	1.236
Some College	0.414	0.490	0.714	1	1.513	0.579	3.953
Employed (ref: Not Employed)	-1.557	0.586	7.066	1	0.211	0.067	0.664
Study Arm (ref: Control)	-0.405	0.433	0.874	1	0.667	0.285	1.559
(Constant)	-2.194	2.281	0.926	1	0.111		

Table 4. Adjusted Logistic Regression: Post-CRA Improved Perceived Lifetime Risk Accuracy (n=394)

	Post-CRA Accurate Lifetime Risk Perception						
						95% CI for EXP(B)	
Variable	*B*	*SE B*	*Wald*	*df*	*Exp(B)*	*Lower*	*Upper*
Numeracy	0.314	0.085	13.671	1	1.369	1.159	1.616
Age (years)	-0.009	0.019	0.239	1	0.991	0.955	1.028
Male Gender (ref: Female)	-0.053	0.241	0.049	1	0.948	0.591	1.522
Race (ref: White)							
Black	-0.970	0.287	11.397	1	0.379	0.216	0.666
Hispanic	-0.718	0.274	6.859	1	0.488	0.285	0.835
Married (ref: Not Married)	0.545	0.226	5.814	1	1.724	1.107	2.685
Education (ref: College Graduate)							
High School Degree or Less	-0.385	0.278	1.925	1	0.680	0.395	1.172
Some College	0.586	0.299	3.850	1	1.797	1.001	3.227
Employed (ref: Not Employed)	0.048	0.240	0.040	1	1.049	0.656	1.679
Pre-CRA Overestimate (ref: Underestimate)	0.393	0.234	2.825	1	1.481	0.937	2.342
Study Arm (ref: Control)	0.231	0.223	1.075	1	1.260	0.814	1.950
(Constant)	-0.458	1.243	0.136	1	0.633		

Table 5. Behavioral Intentions by Post-CRA Perceived Lifetime Risk Accuracy (n=394)

	Mean Intentions (sd)			*Increased Intentions (n* (%))		
Behavior	Improved (n=181)	Inaccurate (n=213)	*p*	Improved (n=181)	Inaccurate (n=213)	*p*
Screening	3.22 (1.5)	3.00 (1.5)	0.135	46 (25.4)	69 (32.4)	0.129
Diet	3.25 (1.1)	3.33 (1.3)	0.512	39 (21.5)	57 (26.8)	0.230
Physical Activity	3.22 (1.1)	3.21 (1.2)	0.972	42 (23.2)	58 (27.2)	0.360

Footnotes

[1] Detailed study procedures can be found in Paper 1.

[2] Qualtrics outsourced recruitment to partner companies with established panels.

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CHAPTER 4

Paper Three

ONLINE PANEL SAMPLE RECRUITMENT AND CHARACTERISTICS: AN ANALYSIS OF THOSE WHO INITIATE VERSUS COMPLETE AN INTERNET SURVEY

Abstract

Background

Using online research panels can be a quick and efficient means of sample acquisition and data collection. Despite this strength, there is often a lack of transparency in the recruitment of panelists and insufficient consideration of how samples derived from online panels compare to relevant populations and other research samples.

Purpose

The purpose of this study was to inform researchers on what to expect when administering an online survey and recruiting participants using quota sampling through a commercial research panel. The sociodemographic characteristics of those who completed the survey were compared to those who initiated but did not complete it. The survey exit point of non-completers was also examined.

Methods

A total of N=419 eligible respondents completed an online survey administered via Qualtrics. In addition to study-specific eligibility criteria, sampling quotas were implemented for race and income.

Results

The majority of panelists who provided consent and were eligible for participation went on to complete the survey. The sociodemographic profiles were similar between survey completers and eligible respondents who initiated but did not complete the survey. Survey completers were relatively similar to the U.S. population 50+ years old. Subtle differences were noted in marital status, income, education, and employment status, but were likely related to the derived sample being more racially and economically diverse. Other implications for the use of quota sampling, the placement of key items, and survey length were discussed.

Conclusion

Quota sampling from an online panel can effectively produce a targeted and diverse sample with reasonable internal and external validity.

Background

Increased use of online (internet) surveys has led to a rise in commercial survey and market research platforms. Companies such as Qualtrics (www.qualtrics.com), Survey Monkey (www.surveymonkey.com), and Amazon's Mechanical Turk (MTurk; www.mturk.com) allow researchers to develop, test, and distribute surveys online. In addition to creating electronic surveys for distribution through typical sample outlets, these companies enable researchers to purchase access to existing pools of potential participants that have agreed to be solicited for survey recruitment. Utilizing online research panels for sample acquisition and data collection is quick and efficient. Compared to traditional survey modes (e.g., mail and telephone), online surveys are typically less expensive [1] and growing evidence suggests that samples recruited through online panels can be as representative of the population as traditional recruitment methods [2-4].

Online research panels can be particularly effective in targeting specific groups, such as respondents who meet a specific condition of interest to the researcher. The use of quota sampling (i.e., a non-probability sampling technique) in online panel research can help researchers obtain survey participants matching specified criteria, such as employed adults or young women aged 18-24 years. Although these are clear advantages, concerns about validity of commercially derived online panel samples have been raised [5-7].

Potential threats to validity come from a variety of sources. Online panel members are recruited from a variety of sources [2] and therefore, precise information on how sampling frames are constructed is usually not available. Selection bias may threaten the external validity of online panels if, for example, panel participants are substantively different than the population

of interest. In addition, racial minorities, older adults, and those with lower levels of educational attainment and income are less likely to have broadband internet service [8]. Although lower income populations may have internet access through a smartphone [9], prior research has shown few panel respondents use smartphones to complete online surveys accessible through multiple platforms (e.g., PC, laptop, tablet, and smartphone) [10]. Online panel samples are also subject to panel bias whereby panelists' responses may change based on their participation in the panel [11]. Because of these potential drawbacks and the relative lack of control researchers have over sample acquisition procedures, a characterization of who panel participants are, how they are recruited, and whether there are differences in those who complete and do not complete an online survey is needed to inform researchers on the validity of online sample panels.

To better understand the treats to validity of these panels, we describe the recruitment and sampling process of an internet-based survey and evaluate the sociodemographic characteristics of the online sample. The specific aims of this study are as follows: (1) to describe the recruitment and participant flow of a survey administered by a commercial research platform using quota sampling; (2) to describe the sociodemographic characteristics of eligible respondents that complete the survey and respondents that initiate, but do not complete the survey; (3) to compare sociodemographic profiles of survey completers to respondents who initiate, but do not complete the survey; and (4) to determine when study-eligible non-completers exit the survey.

Methods

Study Design

The current study followed the pre-post parallel trial design of a previously described study that manipulated the type of information on risk factors (personalized versus generic) for colorectal cancer survey respondents received in addition to average risk estimates.[1] The data reported in this study were collected according to the IRB-approved protocol. The survey contained 133 items with each item requiring a response. Completed survey duration ranged from 10 to 1,922 minutes, with a median duration of 26 minutes. Data collection occurred over a period of 12 days in June 2017 via an internet survey administered by Qualtrics.

Sample and Survey Administration

Qualtrics recruited the sample from existing pools of research panel participants.[2] Recruitment targeted potential survey respondents who were likely to qualify based on the demographic characteristics reported in their user profiles (e.g., race and age). Panelists were sent an email invitation with a unique survey link to the study consent form and survey instrument. To be eligible to participate, respondents had to report being between the ages of 50 and 75 years; no personal or family history of colorectal cancer or other predisposing condition; reading and comprehending English; and residing in the contiguous United States (U.S.). Sampling quotas were implemented for race and annual household income. Specifically, a balanced proportion of respondents with non-Hispanic White, non-Hispanic Black/African

[1] Detailed study procedures can be found in Paper 1.

[2] Qualtrics outsourced recruitment to partner companies with established panels.

American, and Hispanic/Latino/Spanish origin racial/ethnic identities and diversity in reported household income (approximately 20% less than 20k, 30% between 20-49k, 20% between 50-74k, 10% between 75-99k = 10% and 20% greater than or equal to 100k) were requested. Respondents identifying as some other race, ethnicity or origin were not eligible to participate. Ineligible respondents were immediately exited from the survey upon providing a response that did not meet inclusion criteria or exceeded set quotas (i.e., a priori quotas for race or household income group already met). We also removed participants from the sample if they responded incorrectly to any of three "attention checks" included in the survey (i.e., items that instructed respondents to provide a specific response).

Results

Recruitment and Participant Flow

Survey recruitment and participant flow is depicted in Figure 1. The survey was distributed to approximately 63,500 panelists based on target demographics, from which 3,178 interacted with the survey (i.e., clicked on the survey invitation and/or survey link). Among those who interacted with the survey, 1,606 completed the consent page. Of these panelists, 158 did not consent (10%), 671 did not meet eligibility criteria (42%), the majority of whom were ineligible due to health history (n=574 reported a history of colorectal cancer or other predisposing condition). Another 220 respondents screened out due to being over quota (14%). Seventy-one respondents did not complete the survey entirely (4%) and an additional 67 were removed from the study for failing an attention check (i.e., one of three survey items that required specific responses) (4%). A total of n=419 eligible panelists completed the survey (26% of those who completed the consent page).

A priori income quotas proposed for this study were not fully implemented. Due to difficulties acquiring participants who reported an annual household income of ≥100k, we elected to eliminate the income quota after two weeks of data collection. To ensure acquiring the overall sample size required to meet a priori determined criteria for statistical power for the parent study (i.e., n=400), we used natural probability sampling to obtain the remaining number of participants. Ultimately, the final sample consisted of 11% of respondents with ≥100k reported income instead of the 20% initially proposed.

Sample Characteristics

As shown in Table 1, the average age of the n=419 respondents who completed the survey was 58.5 years (sd=6.3). The sample consisted of n=279 females (67%) and as intended, an equal proportion of White, Black, and Hispanic respondents (33% each). Approximately one half of those completing the survey was married (48%), and an equal proportion was college educated (48%). Slightly less than half were employed full or part time (41%). Similarly, slightly less than half reported an annual household income of $50,000 or higher (43%).

In addition to survey completers, Table 1 provides the available sociodemographic characteristics for the four types of respondents who consented but did not complete the survey (i.e., survey non-completers). Non-completers are categorized as: (1) incomplete due to drop out; (2) quality fail (i.e., failed one or more attention check); (3) over quota; and (4) ineligible (i.e., did not meet study inclusion criteria related to health history, race, and age). There was a variable amount of missing data within the non-completer groups as presented in Table 1, depending on when the respondent exited the survey. For example, a respondent over quota due to race/ethnicity (item 4) was missing data for age (item 5) and all items thereafter, while a

respondent quota due to income (item 10) had complete data for all variables described in Table 1.

Additional sample characteristics available on survey completers are presented overall and by racial/ethnic group in Table 2. Black respondents had lower numeracy scores on average and were less likely to be married (34%) relative to White and Hispanic respondents (53-59%). White respondents reported higher income levels and education attainment than minority groups. Hispanics had a higher proportion of currently employed respondents (47%) than the other groups (37-40%).

Comparisons of Completers and Non-Completers

Age.

Qualtrics was able to recruit panelists within the targeted age range reasonably well. Ages within the overall sample ranged from 50-75 years; however, more than half were between 50-60 years old (65%). Only 4% were 71 years and older. The average age of respondents was similar across all groups, ranging from 57 to 62 years. As shown in Figure 1, only n=24 respondents did not meet inclusion criteria for age. Among study-eligible respondent groups (i.e., complete, incomplete, and quality fail), a one-way ANOVA revealed no significant differences in age ($F=2, 550)=1.804$, $p=0.166$.

Gender.

Natural probability sampling resulted in more female respondents than males. The proportion of female respondents was consistently high and similar across all respondent groups, ranging from 66% to 72% female. Among eligible respondents, a chi-square test of

independence was conducted and found no differences in gender by completion status ($X^2(2)=2.005$, $p=0.367$).

Race.

Because the proportion of White, Black, and Hispanic respondents who completed the survey was determined by set quotas, we did not compare this group to others on this criterion. A chi-square test of independence between racial group and the two eligible non-completer groups (i.e., incomplete and quality fail), however, found no statistically significant associations ($X^2(2)=2.272$, $p=0.321$).

The proportion of White respondents was markedly higher in the over quota group relative to other groups (92% versus 20-35%, respectively). This difference results from the use of sampling quotas for race and suggests that the quota for White respondents was met before the quotas for Black and Hispanic respondents.

Income.

Quota sampling was also used to influence the dispersion of reported incomes for survey completers. Therefore, it would not be appropriate to compare completers to non-completers on income. However, a one-way ANOVA was performed between the incomplete and quality fail groups and revealed no statistically significant differences in income, ($F=1, 121)=0.637$, $p=0.426$. There was insufficient data available to describe the ineligible non-completers.

Non-Completer Survey Exit Points

A summary of when study-eligible survey non-completers (i.e., incomplete and quality fail) exited the survey is presented in Table 3. As shown on the top, 21% of the non-completer group

did not progress beyond the initial survey screener items (i.e., “early drop outs”). An additional 59% of the non-completers dropped out during the first half of the survey (prior to receiving risk assessment feedback). These results may indicate the survey was too long to retain interest and engagement for some participants. The remaining 20% of non-completers exited after completing more than half of the survey.

Table 3 also shows a breakdown of the specific items within the screening and pre-test risk perception/health behavior sections, the top areas where incomplete survey respondents exited, which accounted for a combined 58% of the total group. Within the screening section, most stopped completing the survey during health history items. Among those who exited within the pre-test risk perception/health behavior section, respondents were most likely to exit from an item assessing risk perceptions.

Within the quality fail group (see bottom half of Table 3), comprised of study-eligible respondents who failed one of the three attention items, approximately one-quarter failed the first item (28%) and one-quarter failed the second item (22%). Nearly one-half failed the third attention check (49%).

Discussion

This study informs researchers on what to expect when administering an online survey and recruiting participants through a commercial research panel. A thorough description of how quota sampling was used to obtain a racially and economically diverse sample of older adults in a relatively short period of time was provided. Sociodemographic characteristics overall, as well as within and between respondent groups, were examined and provided several indicators of

reasonable sample internal validity. Results provide context and suggestions for future researchers contemplating the use of commercially administered research surveys.

The level of transparency regarding recruitment and participant flow reported in this study (e.g., # emailed, # interacting with the survey, analysis of over quota exclusions, etc.) is greater than that typically reported in other recent studies using online research panels [12-13]. The information outlined indicates that commercial research platforms have access to large panels of research participants. Although more than 60,000 panelists were sent a survey invitation, half of those who interacted with the email ultimately completed the consent page of the survey. Among those who consented and were eligible for participation, most completed the survey (75%). For internet derived samples, this 'completion rate' (i.e., the proportion of survey completers out of all eligible respondents who initiate the survey) is more meaningful than a traditional response rate as unique factors influence panel response that may not be quantifiable by researchers (e.g., inactive panel members and invalid emails) [14]. Health history was the primary reason for ineligibility – a study-specific inclusion criterion. Collectively, these findings indicate that despite contacting higher numbers of potential participants relative to traditional methods, online sampling can target participants based on specific age and race parameters well.

The sociodemographic characteristics of survey completers were consistent with the study inclusion criteria and set quotas (except for the highest income level). Study-eligible respondent groups were similar in age and gender and no significant differences were identified in race and income between study-eligible respondent groups that did not complete the survey, which provides credence for the validity of online panel samples. Furthermore, survey completers overall were similar to the U.S. adult population aged 50 years and older, though somewhat less

likely to be married (48% vs. 60%) and to report a household income of $50,000 or higher (43% vs. 55%) and more likely to possess a college degree (48% vs. 27%) [15]. The resulting sample was also higher in unemployment (59% vs. 47%) compared to nationally representative data [16]. These subtle differences in our sample, i.e., lower household income and higher unemployment, may in part explain the challenge faced in filling the ≥100k income quota.

The proportion of females, often overrepresented in research samples, was somewhat higher among survey completers in this study (67%) compared to that observed in traditional and other online samples within the sample topic area [17-20]. Since other studies have produced more balanced gender proportions without implementing quotas, stratification or quota sampling may be useful but not necessarily required unless the research dictates an equal gender distribution.

Another suggestion can be gleaned from the examination of exit points of the study-eligible respondent groups that did not complete the survey. That more three-quarters of the non-completers exited before the survey halfway point and nearly one-half of the quality fail group failed the final attention check suggests that participants may have lost interest and paid less attention towards the end of the survey. This finding is consistent with best practice guidance to keep surveys – whether traditional or online – as short as possible to increase respondent retention and attentiveness [21-22].

The placement of demographic items is often debated with some recommending that demographic items, such as income and age, not be asked at the beginning of a survey [23-24]. Within this study, all respondents in the non-completer group provided income and only one exited on the age item. Instead, most non-completers exiting within the screening section did so while answering health history items. This result suggests that panel samples may be more

accustomed to and/or comfortable with answering demographic questions than traditional research samples, but may be, nonetheless, sensitive to responding to health-related questions.

It should also be noted that the median survey duration of the non-completer group was over 10,000 minutes (data not shown), substantially higher than the median duration of 26 minutes among those who completed the survey. Qualtrics panelists have the freedom to "walk away" from the survey (e.g. leave survey to answer the door or make dinner). The survey will remain open and incomplete until the respondent returns to complete it or the data collection closes to the study. Because Qualtrics provides transparency on the total survey duration, researchers may consider either excluding responses with excessive duration or removing respondents from the survey after a specified period of inactivity.

Finally, the present study highlights the relative ease of obtaining a racially and economically diverse sample via quota sampling and online recruitment methods. This represents a major advantage over traditional sampling methods that often consist of predominantly White participants [17-19]. Researchers who seek diverse samples should utilize available representative samples whenever possible. When access to minorities is limited, however, online panel sampling using quotas sampling for race may be a valuable approach for reaching minority participants, as demonstrated in this and other panel samples [20, 25].

Strengths and Limitations

This study added transparency to the process of quota sampling and recruiting from an online research panel and provided novel information to researchers about how best to implement future research using these methods. There are, however, a few important study limitations that must be taken into account when interpreting study results. We were unable to

characterize panelists who did not interact with the email invitation. Although this was a large number of individuals, there are likely a variety of reasons for this such as inactive or busy panelists and undeliverable email addresses. Nonetheless, this is an important design factor for future studies wishing to use online panels. The present study was also unable to describe panelists who did not consent for participation. Additional research is needed to explore nonresponse bias in those who do not interact with the survey invitations and decline participation. Among those who consented for participation, relatively few sample characteristics could be compared across respondent groups. For example, marital status could not be assessed across all groups as a result of the order of survey items (e.g., the item assessing marital status was at the end of the survey, after many non-completers had exited the survey). Within the present study, ineligible and over quota respondents were exited from the survey immediately after providing a response that did not meet inclusion criteria or exceeded set quotas. In an effort to address non-response bias and incomplete descriptive characteristics, researchers should purposely include relevant items (e.g., marital status and education) at the beginning of surveys and ask all participants these items, prior to exiting ineligible and over quota respondents from the survey. Future research should also extend the present study by examining psychological and behavioral characteristics of online survey respondent groups.

Conclusion

As the use of online surveys and panel sampling increases, researchers must be cognizant of the strengths and potential pitfalls of using online panels and sampling techniques. Online panel sampling allows researchers to effectively choose study inclusion criteria and implement quotas to obtain racially diverse samples in a shorter period of time than traditional sampling methods.

However, researchers must carefully develop quotas to ensure internal and external validity of the resulting sample. Although higher numbers of potential participants are contacted in online panel sampling, our results suggest that among study-eligible respondents, sociodemographic profiles were similar between survey completers and eligible respondents who initiated but did not complete the survey. This study produced insights into which sample characteristics researchers may want to influence with quota sampling.

Figure 1. Diagram of Recruitment and Participation

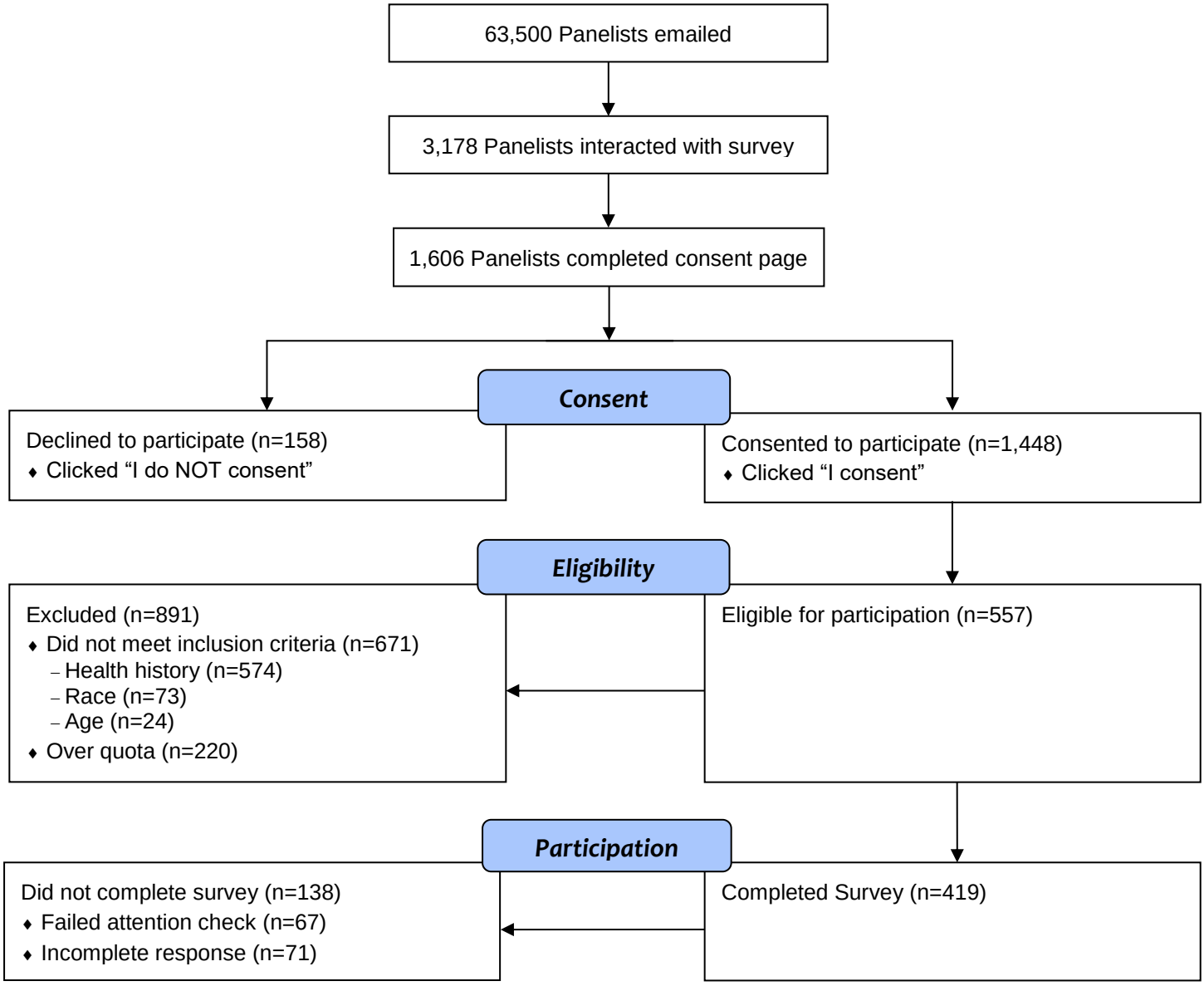

Table 1. Respondent Characteristics (n (%))

	Eligible Respondents			Ineligible Respondents	
	Completers	Non-Completers			
Sociodemographic Variables	Complete (N=419)	Incomplete (n=71)	Quality Fail (n=67)	Over Quota (n=220)	Ineligible (n=671)
Per Eligibility Criteria					
Mean Age (sd)	58.5 (6.3)	57.1 (5.8)	57.6 (6.4)	61.5 (7.2)	58.7 (8.3)
Missing	0	4 (1.0)	0	128 (58.2)	73 (10.9)
Per Quota Sampling					
Race					
White	140 (33.4)	14 (19.7)	16 (23.9)	202 (91.8)	235 (35.0)
Black	140 (33.4)	37 (52.1)	28 (41.8)	12 (5.5)	185 (27.6)
Hispanic	139 (33.2)	17 (23.9)	23 (34.3)	4 (1.8)	178 (26.5)
Other	n/a	n/a	n/a	n/a	73 (10.9)
Missing	0	3 (4.2)	0	2 (0.9)	0
Income					
<20k	94 (22.4)	18 (25.4)	25 (37.3)	19 (8.6)	no data
20-49k	145 (34.6)	21 (29.6)	26 (38.8)	41 (18.6)	no data
50-74k	90 (21.5)	10 (14.1)	9 (13.4)	18 (8.2)	no data
75-99k	46 (11.0)	2 (2.8)	3 (4.5)	6 (2.7)	no data
≥100k	44 (10.5)	5 (7.0)	4 (6.0)	2 (0.9)	no data
Missing	0	15 (21.1)	0	134 (60.9)	no data
Natural Probability					
Gender					
Female	279 (66.6)	51 (71.8)	44 (65.7)	156 (70.9)	440 (65.6)
Male	140 (33.4)	17 (23.9)	23 (34.3)	62 (28.2)	231 (34.4)
Missing	0	3 (4.2)	0	2 (0.9)	0

Note. Values may not equal total sample size or 100% due to rounding and missing data.

Table 2. Survey Completer Characteristics by Race/Ethnic Group (n (%))

Variable	Overall (N=419)	White (n=71)	Black (n=67)	Hispanic (n=220)
Sociodemographic				
Mean Age (sd)	58.5 (6.3)	60.1 (6.6)	58.5 (5.9)	57.0 (6.0)
Female Gender	279 (66.6)	89 (63.6)	95 (67.9)	95 (68.3)
Currently Married[a]	203 (48.4)	82 (58.6)	48 (34.3)	73 (52.5)
Income				
<20k	94 (22.4)	25 (17.9)	36 (25.7)	33 (23.7)
20-49k	145 (34.6)	42 (30.0)	57 (40.7)	46 (33.1)
50-74k	90 (21.5)	24 (17.1)	33 (23.6)	33 (23.7)
75-99k	46 (11.0)	25 (17.9)	8 (5.7)	13 (9.4)
≥100k	44 (10.5)	24 (17.1)	6 (4.3)	14 (10.1)
College Graduate	203 (48.4)	78 (55.7)	58 (41.4)	67 (48.2)
Currently Employed[b]	173 (41.3)	56 (40.0)	52 (37.1)	65 (46.8)
Insured	368 (87.8)	128 (91.4)	124 (88.6)	116 (83.5)
English Language[c]	400 (95.5)	139 (99.3)	140 (100.0)	121 (87.1)
Other				
Mean Numeracy (sd)[d]	1.0 (0.9)	1.3 (1.0)	0.6 (0.8)	1.0 (0.9)
Mean Health Status (sd)[e]	3.2 (0.9)	3.3 (1.0)	3.0 (0.8)	3.2 (0.9)
Mean Health Literacy (sd)[f]	4.5 (0.8)	4.5 (0.8)	4.6 (0.7)	4.5 (0.7)

Note.

[a] Currently married or living with significant other

[b] Currently employed full-time or part-time

[c] English is primary language spoken at home

[d] Assessed using 3-item scale developed by Schwartz and colleagues [26]

[e] Assessed on a 5 point Likert scale, with answers ranging from Poor (1) to Excellent (5)

[f] Assessed on a 5 point Likert scale, with answers ranging from Not At All (1) to Extremely (5)

Table 3. Study-Eligible Non-Completer Survey Exit Points

Survey Section	Item Numbers	Respondents Exited (n (%))
Incomplete Group (n=71)		
Screening	1-10	15 (21.1)
Did not start survey		3 (20.0)
Gender		0 (0.0)
Race		0 (0.0)
Age		1 (6.7)
Colon health history		8 (53.3)
Breast health history		3 (20.0)
Income		0 (0.0)
Risk Perceptions and Health Behaviors (pre-test)	11-41	26 (36.6)
Did not start section		8 (30.8)
Risk perceptions		13 (50.0)
Health behaviors		5 (19.2)
Numeracy	42-48	12 (16.9)
Lifestyle Behaviors	49-69	4 (5.6)
Survey Halfway Point		
Risk Assessment Feedback	70-90	2 (2.8)
Risk Perceptions and Health Behaviors (post-test)	91-114	11 (15.5)
Demographics	115-128	1 (1.4)
Satisfaction	129-133	0 (0.0)
Quality Fail Group (n=67)		
First Attention Item	33	19 (28.4)
Second Attention Item	64	15 (22.4)
Third Attention Item	108	33 (49.3)

Note. Values may not equal total 100% due to rounding.

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CHAPTER 5

Conclusion

Summary

CRC is the second leading cause of cancer-related mortality in the U.S., accounting for approximately 50,000 deaths annually [1]. Although the average lifetime risk of CRC is relatively low, the majority of CRC cases occur among those at average risk - with no personal or family history of the disease [2]. Therefore, it is imperative that those at average risk perceive CRC as a formidable threat and take actions to prevent the disease. The present study was conducted to assess whether providing personalized CRC risk assessment feedback including behavior change messages would alter risk perceptions and drive risk-reducing behavioral intentions among those at average risk and age-eligible for screening.

Through a series of related papers, this dissertation evaluated the impact of CRC risk assessment feedback. The first paper evaluated the effects of providing personalized (vs. generic) risk assessment feedback on individuals' risk perceptions and intentions to engage in three risk-reducing behaviors. This paper also answered a novel question of whether the provision of CRC risk information alters perceptions and intentions of a different cancer, breast cancer, which also has strong lifestyle based risks and population based screening programs. The second paper examined individuals' accuracy of perceived lifetime risk of CRC and assessed whether improved accuracy was associated with behavior change intentions following risk assessment feedback. Finally, the third paper described and evaluated the sampling procedures and survey respondent groups of this research. Overall, several significant findings emerged from these three papers.

Results provided support for the potential role cancer risk assessments may play in promoting cancer screening behaviors. That colorectal cancer screening intentions increased after receiving risk assessment feedback is particularly remarkable within this average risk sample given that: (1) as average risk, having reported no history of CRC, participants were provided with a low estimate of lifetime risk (less than 5%); and (2) only half of the sample was currently up-to-date according to current screening guidelines and this group can be hard to influence as they report more perceived barriers to screening than those who have had a recent screening test [2]. Finally, this finding is noteworthy because (3) it suggests that personalized risk assessment feedback, which may be more time and resource intensive, was not necessary to produce significant increases in screening intentions since changes occurred in both intervention arms.

While improving screening intentions is a positive outcome, it should be emphasized that intentions related to diet and physical activity improvement were not similarly impacted. One plausible explanation underlying this outcome is that screening may be perceived as a "one and done" behavior to reduce CRC risk, while changes in diet and physical activity inherently require ongoing lifestyle modification. Common barriers to screening include knowledge gaps and structural barriers [3], which can be overcome with narrowly-focused interventions, whereas lifestyle changes require more complex interventions, providing support and strategies to improve skills and motivation for ongoing change to daily routines and behaviors [4-5]. Therefore, it may be that those with lifestyle risk factors would indicate intentions to screening simply because it is the "easier" opportunity to mitigate one's cancer risk.

It should also be acknowledged that increased intervention dosage (i.e., repeated exposures to messages) is often necessary to increase desired effects [6]. While low intensity interventions, such as patient and provider reminders, have produced favorable changes in CRC screening behaviors [7-8], the single message "dose" provided in this study may have been insufficient to produce changes in intent for the behaviors requiring continuous changes. A systematic review of dietary and physical activity interventions supports this suspicion; with results indicating effectiveness was associated with increased intervention intensity (e.g., number of sessions, frequency of contacts, etc.) and the use of specific behavior change techniques [9].

A third possible explanation for the lack of changes in diet and physical activity intentions is that the conceptual pathway underlying the expected outcome was not supported. Specifically, it was hypothesized that the provision of personalized risk information would increase risk perceptions and subsequently, promote higher behavioral changes intentions to mitigate heightened perceptions of risk. Instead of producing increased risk perceptions as hypothesized, perceived lifetime risk of CRC lowered within both arms. This outcome is not entirely surprising given that the sample was comprised of average risk individuals and because people tend to regard their own risk optimistically and will reduce perceptions of their own risk to maintain the belief that their risk is lower than average [10-11].

The reduction in perceived lifetime risk reflected improved accuracy following risk assessment, a finding consistent with prior studies [12-15]. This dissertation built upon this foundation by characterizing who benefited from improved accuracy and assessing if improvement in lifetime risk accuracy (at follow up) was associated with changes in behavioral intentions. Our findings revealed there was significantly less improvement in accuracy among

Blacks and Hispanics (compared to Whites) and individuals with low numeracy. This result suggests that different risk communication strategies may be needed for groups who are traditionally disadvantaged in the healthcare area. Prior research has shown that interventions are more effective when they are culturally appropriate including, for example, language- and race/ethnicity-concordant counselors, messages, and materials [17-20]. Therefore, the accuracy of minority respondents conceivably could have been improved if the present study provided tailored messages based on known cultural factors (e.g., religiosity, racial identity/pride, family context) [18-19, 21-22]. This adds to the body of literature promoting cultural relevance in health interventions targeting racial/ethnic minorities and extends message tailoring guidance to researchers working with diverse samples. Future research should attempt to tease out the different pathways underlying differences in risk perception accuracy in different racial/ethnic and numeracy groups.

Although negative outcomes have been linked to inaccurate risk perceptions and accuracy is generally regarded as inherently positive [11], the current body of research has not thoroughly explored how risk perception accuracy is related to health outcomes [13-16]. We found no association between perceived lifetime risk accuracy and behavior change intentions for any of the three behavioral outcomes measured. This null result is noteworthy because accuracy was achieved through a decrease in perceived risk and thus, conceivably could have had a detrimental impact. Within this study in which roughly one quarter of participants reported increased intentions to perform risk-reducing behaviors, improved accuracy via a decreased perception of risk appears to have neither promoted nor inhibited intentions to adopt health behaviors. These results underscore the need for qualitative research to better understand how risk perceptions and

behavioral intentions are influenced within the context of risk assessment among those at average risk.

The sample recruited in this research was purposely racially and economically diverse because there are known differences in CRC outcomes, screening behaviors, and risk perceptions by race and socioeconomic status [23-28]. Since samples acquired through traditional means often consist of mostly White participants [29-31], the current study intentionally enrolled over-represented minority groups in order to garner broad perspectives on cancer risk assessment feedback. Future research is planned to examine whether known differences in racial/ethnic groups are present within this dataset. However, the sociodemographic characteristics of this diverse sample of older adults were compared and several indicators of reasonable sample internal validity and external generalizability were found, including limited differences between respondent groups and between respondents who completed the survey and the U.S. population aged 50 years and older. Taken together, this study provided support for using quota sampling of an online panel to acquire a targeted and diverse sample that may have otherwise been difficult to recruit in a relatively short period of time.

Finally, perhaps the most intriguing finding of this dissertation was that risk assessment feedback for a specific cancer type produced ‘spillover effects’ on another cancer type. While no information was provided related to breast cancer, female participants’ perceived lifetime risk of breast cancer lowered and mammography screening intentions increased among those provided generic risk information. This finding suggests that generic feedback may be more likely to produce spillover effects. Prior research has also indicated that not only is cancer screening uptake correlated with the use of other preventative screenings, but that past uptake of either

breast or cervical cancer screening directly influences the uptake of screening for the other cancer [32]. Furthermore, psychological theory (e.g., cognitive dissonance and the theory of self-perception) offers potential insights on spillover effects, stating that people tend to think and act in consistent ways [33-34]. Therefore, it is conceivable that an intervention that prompts increased screening intentions for one cancer type would amplify screening intentions for another cancer type, and would similarly produce a consistent impact on cancer risk perceptions. Cancer prevention and risk communication professionals should be cognizant of the potentially positive or negative public health implications of unintended consequences resulting from risk assessment feedback. In order to leverage spillover effects in such a way that intensifies the magnitude of cancer prevention efforts, future research is warranted to understand whether and under what conditions positive and negative spillover effects occur. Focusing on both CRC and breast cancer screening behaviors may be particularly beneficial, as these two cancers combined account for nearly 40 percent of all cancers in women [1]. This result, while preliminary, may indicate that generic feedback on risk factors (including screening) is more likely to produce spillover screening intentions on another cancer screening type.

Strengths and Limitations

The primary strength of this dissertation is the focus on an average risk population of adults. This group is largely understudied in risk communication research despite being the population in which most CRC cases occur. Future research should target this group and aim to uncover new ways to promote their interest in adopting risk-reducing lifestyles and behaviors. A second strength related to the sample is that it was both racially and economically diverse, a major advantage over much of the literature base that is comprised of predominately White sample.

However it should be noted that the sample heterogeneity may have played a role in the null results observed. As previously mentioned, the present study was potentially limited in that we did not address the sample diversity in our personalized messages and because there was variation in the personalization of risk messages provided in the treatment arm (depending on participant reported engagement in behaviors). Nonetheless, that this dissertation included an emphasis on minority participation and focused on nuances of research methods that are commonly overlooked in the literature (e.g., quota sampling and recruitment from online research panels) represents a strength over other studies.

Before providing final conclusions, it is important to acknowledge a few limitations of this research. The main limitation of this dissertation is that the numeric estimates of lifetime risk provided to participants were the average lifetime risk of CRC according to gender in the U.S., and as such, were not fully personalized based on each individuals' reported risk factors. As average risk, these estimates would not have change substantially for most. None the less the impact of providing person-specific lifetime risk estimates is not known.

Another chief limitation of this study is related to how accuracy of lifetime risk perception was defined. Defined as between four and five percent [35], the range for accuracy was relatively narrow. A wider approximate for accuracy (e.g., +/– 5%) may have changed the results and implications of this research. In addition, awareness of personal risk factors putting oneself at higher than average risk (e.g., eating large amounts of red and process meats or drinking heavily) may have influenced respondent reports of lifetime risk and artificially reduced the number of participants considered having an accurate perception. It should also be considered that it may not be that one's actual perception of their lifetime risk changed per se as their ability to recall

the information changed their response to the question. It was not assessed if participants believed the risk estimate information they were given. Further, it is not known if improved accuracy remained stable over time. Longitudinal or additional follow-up assessment of accuracy is needed to detect changes in accuracy and to examine what, if any, association these changes would have with intention for behavior change.

Another important limitation of this dissertation is that assessment of behaviors was outside the scope of the study. While behavioral intentions were used as proxy and previous research supports an association between intentions and completed colorectal cancer screening [36-37], it should be acknowledged that intentions do not always translate to actual changes in behavior. Finally, it was not possible to examine some of the characteristics of different respondent groups due to low or missing data. In order to better assess non-response bias, future research should ensure that variables of interest are asked to all respondents to the extent possible.

Conclusion

Communicating CRC risk information to average risk adults increased CRC-specific perceived lifetime risk accuracy and screening intentions. Breast cancer lifetime risk perceptions and mammography screening intentions (within the control arm) were also altered among female participants. In this study, neither personalized information about risk factors nor improved accuracy of lifetime risk were associated with changes in intentions to perform risk reducing behaviors, supporting the old adage that knowledge is necessary but not sufficient to drive behavior change. Collectively, results support the notion that 'moving the needle' in lifestyle modification toward CRC prevention is difficult – especially among those with no known family history of the disease. Despite the magnitude of the challenges facing cancer prevention

researchers, future efforts must continue to develop innovative strategies to prevent CRC as it remains a fierce threat that must be addressed. Issues related to the prevention paradox will likely persist until better population approaches to cancer risk communication are developed. Continued message testing and development is needed related to risk communication, especially within minority and low numeracy groups. Future studies could use online survey administration and panel sampling, as findings from this research highlighted the ability of these methods to produce targeted samples quickly and with reasonable internal validity and external generalizability.

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APPENDIX

FINAL Dissertation RAQ - for distribution 6.19.17

Start of Block: Consent

Q1 RESEARCH PARTICIPANT INFORMATION AND CONSENT FORM

TITLE: Colorectal Risk Assessment among Average Risk Adults

VCU IRB PROTOCOL NUMBER: HM20009815

INVESTIGATOR: Maria Thomson, PhD

If any information contained in this consent form is not clear, please contact the study staff to explain any information that you do not fully understand.

PURPOSE OF THE STUDY

The purpose of this research study is to learn more about how people understand and use risk information about colorectal cancer that is presented in different ways. You are being asked to participate in this study because you are an adult between 50-75 years of age living in the United States.

DESCRIPTION OF THE STUDY AND YOUR INVOLVEMENT

This is a survey study. If you decide to be in this research study, you will be asked to click on the "agree" button to electronically consent after you have had all your questions answered and understand what will happen to you.

If you agree to participate, you will be randomly assigned to one of two groups. Each group will answer the same set of questions related to colorectal cancer and receive risk information that will be presented in one of two ways, depending on your group assignment. After viewing the risk results, you will be asked to complete a set of follow-up questions. The survey will ask your opinions about cancer prevention, your attitudes and beliefs related to colorectal cancer specifically, and related preventive health behaviors and intentions, as well as demographic questions. The entire survey will take approximately 30 minutes to complete.

RISKS AND DISCOMFORTS

There are no physical risks associated with this study. We do not foresee any significant risks or discomfort to your participation. However, it is possible that some questions could be distressing to some people, such as questions relating to their personal and family history of cancer. In addition, participants will receive a numeric risk indicator, which some participants may find upsetting.

If you choose to participate in this study, please keep in mind that if you do become uncomfortable and do not wish to answer the survey questions, you may stop at any time by exiting the survey.

BENEFITS TO YOU AND OTHERS

You may not receive any direct benefits by participating in this research, but you may get the opportunity and satisfaction of learning more about and contributing to research in this field.

COSTS

There are no costs for participating in this study other than the time you will spend filling out the online survey.

PAYMENT FOR PARTICIPATION

Survey respondents will receive compensation for participation. You will receive the agreed upon incentive provided by Qualtrics after completing the survey. There will be no payment for incomplete surveys, meaning you will not receive compensation if you choose to exit the study prior to completing the survey in its entirety.

ALTERNATIVES

The alternative to participating in this study is to not participate.

CONFIDENTIALITY

The surveys will be administered online via Qualtrics. Data collected in the survey is completely anonymous, meaning that there is no way to connect your identity to your responses. Survey data will be maintained on a HIPAA secured computer and drive; no identifying information or keys will be included. The results of this study may be used in reports, presentations, or publications, but your name will not be used.

VOLUNTARY PARTICIPATION AND WITHDRAWAL

Your participation is voluntary. You may decide not to participate in this study. Your decision not to take part will involve no penalty or loss of benefits to which you are otherwise entitled.

If you choose to participate, you may stop at any time without any penalty. However, participation involves answering all survey questions, including potentially sensitive questions (i.e., questions related to their personal and family history of cancer). Thus, you will not receive compensation if you choose to exit the study prior to completing the survey in its entirety.

QUESTIONS
If you have any questions, complaints, or concerns about your participation in this research, contact the Principal Investigator:

Maria Thomson, PhD at Maria.Thomson@vcuhealth.org.

The researcher named above is the best person to contact for questions about your participation in this study.

If you have any general questions about your rights as a participant in this or any other research, you may contact:

Office of Research
Virginia Commonwealth University
800 East Leigh Street, Suite 3000
P.O. Box 980568
Richmond, VA 23298
Telephone: (804) 827-2157

Contact this number for general questions, concerns or complaints about research. You may also call this number if you cannot reach the research team or if you wish to talk with someone else. General information about participation in research studies can also be found at http://www.research.vcu.edu/irb/volunteers.htm.
CONSENT I have been provided with an opportunity to read this consent form carefully.

By clicking the "I consent" button, I have not waived any of the legal rights or benefits, to which I otherwise would be entitled. My clicking indicates that I freely consent to participate in this research study.

- ○ I consent (1)
- ○ I do NOT consent (0)

Skip To: End of Block If RESEARCH PARTICIPANT INFORMATION AND CONSENT FORM TITLE: Colorectal Risk Assessment among Aver... = I do NOT consent

End of Block: Consent

Start of Block: Screening Qs

Q2 **Welcome!** The following survey is about your attitudes and behaviors related to colorectal cancer. Colorectal cancer is cancer of the colon (large bowel, large intestine) or rectum. **Please answer each question to the best of your ability.** Remember, these questions are about your

attitudes and behaviors; there are no “right” or “wrong” answers to these questions. Thank you for taking the time to complete this survey.

Page Break

X→

Q3 Are you male or female?

- ○ Male (1)
- ○ Female (0)

X→ X→

Q4 Which of the following categories best describes you?

- ○ White (1)
- ○ Black or African American (2)
- ○ Hispanic, Latino, or Spanish origin (3)
- ○ Some other race, ethnicity, or origin (4)

Skip To: End of Block If Which of the following categories best describes you? = Some other race, ethnicity, or origin

*

Q5 What is your age (in years)?

_____

Skip To: End of Block If What is your age (in years)? <= 49

Skip To: End of Block If What is your age (in years)? >= 76

Page Break

X→ X→

Q6 Have you ever been told by a doctor or other healthcare provider that you have **polyps in your colon or rectum**? Polyps are small growths that are not cancerous but are often removed to prevent cancer from developing.

- ○ Yes (1)
- ○ No (0)

Skip To: End of Block If Have you ever been told by a doctor or other healthcare provider that you have polyps in your col... != No

X→ X→

Q7 Have you ever been told by a doctor or other healthcare provider that you have **colon cancer** (cancer of the large bowel, large intestine, or rectum?

- ○ Yes (1)
- ○ No (0)

Skip To: End of Block If Have you ever been told by a doctor or other healthcare provider that you have colon cancer (canc... != No

X→ X→

Q8 **Please indicate if any of the following statements are true for you:**

I have a history of inflammatory bowel disease (e.g. ulcerative colitis or Crohn's disease). (Q8_1)	▼ Yes (1) ... No (2)
At least one of my parents, siblings, or children has been told they have polyps or colorectal cancer. (Q8_2)	▼ Yes (1) ... No (2)
I have a known family history of a hereditary colorectal cancer syndrome such as familial adenomatous polyposis (FAP) or hereditary nonpolyposis colon cancer (HNPCC), also known as Lynch Syndrome. (Q8_3)	▼ Yes (1) ... No (2)

Skip To: End of Block If Please indicate if any of the following statements are true for you: != At least one of my parents, siblings, or children has been told they have polyps or colorectal cancer.

Skip To: End of Block If Please indicate if any of the following statements are true for you: != At least one of my parents, siblings, or children has been told they have polyps or colorectal cancer.

Skip To: End of Block If Please indicate if any of the following statements are true for you: != At least one of my parents, siblings, or children has been told they have polyps or colorectal cancer.

Display This Question:

If Are you male or female? = Female

X→ X→

Q9 **Please indicate if any of the following statements are true for you:**

I have at least one first-degree relative (e.g., mother, sisters, or daughters) who has been told they have breast cancer. (Q9_1)	▼ Yes (1) ... No (2)
I have a known or suspected mutation in either the BRCA1 or BRCA2 gene or an inherited cancer-causing syndrome, such as the Li-Fraumeni syndrome. (Q9_2)	▼ Yes (1) ... No (2)

Q10 Which of the following ranges best describes your household's total income (before taxes) in the previous year?

- ○ Less than $20,000 (1)
- ○ $20,000 to $49,999 (2)
- ○ $50,000 to $74,999 (3)
- ○ $75,000 to $99,999 (4)
- ○ $100,000 or more (5)

Page Break

End of Block: Screening Qs

Start of Block: PRE-RP Group 1

Q11
YOU AND COLON CANCER

On a scale from 0 to 100 %, how would you rate the probability that you will develop colorectal cancer in the future?

_____

Q12

	Very unlikely (1)	Unlikely (2)	Neither likely nor unlikely (3)	Likely (4)	Very likely (5)
How likely is it that you will get colorectal cancer at some point in the future? (Q12)	○	○	○	○	○

Q13

	Much lower (1)	A little lower (2)	The same (3)	A little higher (4)	Much higher (5)
How do you think your chance of developing colorectal cancer in the future compares to the average person of your gender and age? (Q13)	○	○	○	○	○

Q14

	Very low (1)	Low (2)	Neither low nor high (3)	High (4)	Very High (5)
The way I look after my health means that my odds of getting colorectal cancer in the future are: (Q14)	○	○	○	○	○

End of Block: PRE-RP Group 1

Start of Block: PRE-RP Group 2

Q15

	Not at all (1)	A little (2)	A moderate amount (3)	A lot (4)	Extremely (5)
How **worried** are you about developing colorectal cancer in the future? (Q15_1)	○	○	○	○	○
How **fearful** are you about developing colorectal cancer in the future? (Q15_2)	○	○	○	○	○
How **nervous** are you about developing colorectal cancer in your lifetime? (Q15_3)	○	○	○	○	○
How **concerned** are you about developing colorectal cancer in your lifetime? (Q15_4)	○	○	○	○	○
How **easy** is it for you to imagine yourself developing colorectal cancer in the future? (Q15_5)	○	○	○	○	○

When you think about colorectal cancer for a moment, to what extent do you feel **fearful**? (Q15_6)	○	○	○	○	○
When you think about colorectal cancer for a moment, to what extent do you feel **worried**? (Q15_7)	○	○	○	○	○
When you think about colorectal cancer for a moment, to what extent do you feel **anxious**? (Q15_8)	○	○	○	○	○

End of Block: PRE-RP Group 2

Start of Block: PRE-RP Group 3

Q16

	Strongly disagree (1)	Disagree (2)	Neither agree nor disagree (3)	Agree (4)	Strongly agree (5)
When I think carefully about my lifestyle it does seem possible that I could get colorectal cancer. (Q16_1)	○	○	○	○	○
If I look at myself as if I were a doctor, I realize that my behavior puts me at risk of getting cancer. (Q16_2)	○	○	○	○	○
I feel very vulnerable to colorectal cancer. (Q16_3)	○	○	○	○	○
I am confident that I will not get colorectal cancer. (Q16_4)	○	○	○	○	○
I would be lying if I said “There is no chance of me getting colorectal cancer.”	○	○	○	○	○

(Q16_5) My first reaction when I hear of someone getting colorectal cancer is “that could be me someday.” (Q16_6)	○	○	○	○	○

End of Block: PRE-RP Group 3

Start of Block: PRE-BCA RP

Q17
YOU AND BREAST CANCER

On a scale from 0 to 100 %, how would you rate the probability that you will develop BREAST cancer in the future?

_____

Q18

	Very unlikely (1)	Unlikely (2)	Neither likely nor unlikely (3)	Likely (4)	Very likely (5)
How likely is it that you will get BREAST cancer at some point in the future? (Q18)	○	○	○	○	○

X→ X→

Q19

	Much lower (1)	A little lower (2)	The same (3)	A little higher (4)	Much higher (5)
How do you think your chance of developing BREAST cancer in the future compares to the average person of your gender and age? (Q19)	○	○	○	○	○

End of Block: PRE-BCA RP

Start of Block: PRE-DEM RP

*

Q20
YOU AND DEMENTIA

On a scale from 0 to 100 %, how would you rate the probability that you will develop DEMENTIA in the future?

_____

Q21

	Very unlikely (1)	Unlikely (2)	Neither likely nor unlikely (3)	Likely (4)	Very likely (5)
How likely is it that you will get DEMENTIA at some point in the future? (Q21)	○	○	○	○	○

Q22

	Much lower (1)	A little lower (2)	The same (3)	A little higher (4)	Much higher (5)
How do you think your chance of developing DEMENTIA in the future compares to the average person of your gender and age? (Q22)	○	○	○	○	○

End of Block: PRE-DEM RP

Start of Block: Screening HX

Q23
CANCER SCREENING TESTS

The next few questions are about some different tests you may have already had to look for signs of cancer.

Display This Question:

If Are you male or female? = Female

X→ X→

Q24

A MAMMOGRAM is an x-ray picture of the breast.
Have you ever had a mammogram?

- ○ Yes (1)
- ○ No (0)
- ○ I Don't Know (9)

Display This Question:

If A MAMMOGRAM is an x-ray picture of the breast. Have you ever had a mammogram? = Yes

X→ X→

Q25 When was your most recent **mammogram**?

- ○ 2 years ago or less (1)
- ○ More than 2 years ago (2)

X→ X→

Q26

FECAL OCCULT BLOOD TEST (FOBT)

A FOBT IS DONE AT HOME to determine whether your stool contains blood. You take small samples of your fecal matter or stool and return the sample to be tested.

Have you ever had one of these stool blood tests?

- ○ Yes (1)
- ○ No (0)
- ○ I Don't Know (9)

Display This Question:

If FECAL OCCULT BLOOD TEST (FOBT) A FOBT IS DONE AT HOME to determine whether your stool contains... = Yes

X→ X→

Q27 When was your most recent **FOBT**?

- ○ 1 year ago or less (1)
- ○ More than 1 year ago (2)

Page Break

Q28
The next two questions are about sigmoidoscopy and colonoscopy. Both tests examine the colon using a narrow, lighted tube that is inserted in the rectum.

X→ X→

Q29

SIGMOIDOSCOPY
A sigmoidoscopy (pronounced: sig-MOY-DAHS-kuh-pee) is also referred to as flexible sigmoidoscopy or "flex sig." Sigmoidoscopy examines only the lower part of the colon. You are awake during the test, can drive yourself home, and can resume normal activities after the test. **Have you ever had a sigmoidoscopy?**

- ○ Yes (1)
- ○ No (0)
- ○ I Don't Know (9)

Display This Question:

If SIGMOIDOSCOPY A sigmoidoscopy (pronounced: sig-MOY-DAHS-kuh-pee) is also referred to as flexibl... = Yes

X→ X→

Q30 When was your most recent sigmoidoscopy?

- ○ 1 year ago or less (1)
- ○ More than 1 but not more than 5 years ago (2)
- ○ More than 5 but not more than 10 years ago (3)
- ○ More than 10 years ago (4)

Q31

COLONOSCOPY

A colonoscopy (pronounced: koh-luh-NAHS-kuh-pee) is a test that uses a narrow, lighted tube to examine the entire colon. With a colonoscopy, you are sleepy or asleep during the test, need someone to drive you home, and need to take the rest of the day off from normal activities.

Have you ever had a colonoscopy?

- Yes (1)
- No (0)
- I Don't Know (9)

Display This Question:

If COLONOSCOPY A colonoscopy (pronounced: koh-luh-NAHS-kuh-pee) is a test that uses a narrow, ligh... = Yes

Q32 When was your most recent colonoscopy?

- 1 year ago or less (1)
- More than 1 but not more than 5 years ago (2)
- More than 5 but not more than 10 years ago (3)
- More than 10 years ago (4)

Q33 To make sure you are paying attention, please answer yes for this question.

- ○ Yes (1)
- ○ No (0)
- ○ I Don't Know (9)

Skip To: End of Block If To make sure you are paying attention, please answer yes for this question. != Yes

End of Block: Screening HX

Start of Block: PRE-BI

Q34
HEALTH BEHAVIORS

	Not at all (1)	A little (2)	A moderate amount (3)	A lot (4)	Extremely (5)
CRCS UTD != 1 How likely are you to get tested for colorectal cancer in the next 6 months? (Q34_1)	○	○	○	○	○
CRCS UTD = 1 How likely are you to get tested for colorectal cancer (when you are due to be tested again)? (Q34_2)	○	○	○	○	○
Are you male or female? = Female *And Mammo UTD != 1* How likely are you to get a mammogram in the next 6 months? (Q34_3)	○	○	○	○	○
Are you male or female? = Female *And Mammo*	○	○	○	○	○

UTD = 1					
How likely are you to get a mammogram (when you are due to get a mammogram again)? (Q34_4)					
How likely are you to improve your diet in the next 6 months? (Q34_5)	○	○	○	○	○
How likely are you to increase your physical activity in the next 6 months? (Q34_6)	○	○	○	○	○
How likely are you to talk to a doctor about getting tested for colorectal cancer in the next 6 months? (Q34_7)	○	○	○	○	○

Page Break

Q35 Do you have a **healthy diet**?

- YES, I have a healthy diet and I have for MORE than 6 months. (1)
- YES, I have a healthy diet and I have for LESS than 6 months. (2)
- NO, but I intend to improve my diet in the next 30 days. (3)
- NO, but I intend to improve my diet in the next 6 months. (4)
- NO, and I do NOT intend to improve my diet in the next 6 months. (5)

Q36 Are you **physically active**?

- YES, I am physically active and I have been for MORE than 6 months. (1)
- YES, I am physically active and I have been for LESS than 6 months. (2)
- NO, but I intend to increase my physical activity in the next 30 days. (3)
- NO, but I intend to increase my physical activity in the next 6 months. (4)
- NO, and I do NOT intend to increase my physical activity in the next 6 months. (5)

Q37 Do you screen for **colorectal cancer** regularly (as recommended by your healthcare provider)?

- ○ YES, I screen for colorectal cancer regularly, AND I intend to get screened for colorectal cancer when I am due again. (1)
- ○ YES, I screen for colorectal cancer regularly, BUT I do NOT intend to get screened for colorectal cancer when I am due again. (2)
- ○ NO, but I intend to get screened for colorectal cancer in the next 30 days. (3)
- ○ NO, but I intend to get screened for colorectal cancer in the next 6 months. (4)
- ○ NO, and I do NOT intend to get screened for colorectal cancer in the next 6 months. (5)

Display This Question:

If Are you male or female? = Female

Q38 Do you screen for **breast cancer** regularly (as recommended by your healthcare provider)?

- ○ YES, I screen for breast cancer regularly, AND I intend to get screened for breast cancer when I am due again. (1)
- ○ YES, I screen for breast cancer regularly, BUT I do NOT intend to get screened for breast cancer when I am due again. (2)
- ○ NO, but I intend to get screened for breast cancer in the next 30 days. (3)
- ○ NO, but I intend to get screened for breast cancer in the next 6 months. (4)
- ○ NO, and I do NOT intend to get screened for breast cancer in the next 6 months. (5)

End of Block: PRE-BI

Start of Block: Self-Efficacy

Q39
ATTITUDES AND BELIEFS

	Very difficult (1)	Difficult (2)	Neither easy nor difficult (3)	Easy (4)	Very easy (5)
For me, **improving my diet** in the next 6 months would be: (Q39_1)	○	○	○	○	○
For me, **increasing my physical activity** in the next 6 months would be: (Q39_2)	○	○	○	○	○
For me, **getting tested for colorectal cancer** in the next 6 months would be: (Q39_3)	○	○	○	○	○

Q40

	Strongly disagree (1)	Disagree (2)	Neither agree nor disagree (3)	Agree (4)	Strongly agree (5)
If I wanted to, I could easily **improve my diet** in the next 6 months. (Q40_1)	○	○	○	○	○
If I wanted to, I could easily **increase my physical activity** in the next 6 months. (Q40_2)	○	○	○	○	○
If I wanted to, I could easily **get tested for colorectal cancer** in the next 6 months. (Q40_3)	○	○	○	○	○

End of Block: Self-Efficacy

Start of Block: PRE-Beliefs/AVOID, and NUM

X→ X→

Q41 **How much do you agree or disagree with each of the following statements?**

	Strongly disagree (1)	Disagree (2)	Neither agree nor disagree (3)	Agree (4)	Strongly agree (5)
Cancer is most often caused by a person's behavior or lifestyle. (Q41_1)	○	○	○	○	○
It seems like everything causes cancer. (Q41_2)	○	○	○	○	○
There's not much you can do to lower your chances of getting cancer. (Q41_3)	○	○	○	○	○
There are so many different recommendations about preventing cancer, it's hard to know which ones to follow. (Q41_4)	○	○	○	○	○
I'd rather not know my chance of getting cancer. (Q41_5)	○	○	○	○	○

Page Break

Q42
CHANCE AND PROBABILITIES

Q43
Please answer the following questions to the best of your ability and give your responses in NUMBERS ONLY - no words or symbols (i.e., 12, not "twelve").

Q44 Imagine that we rolled a fair, six-sided die 1,000 times. Out of 1,000 rolls, how many times do you think the die would come up even (2, 4, or 6)?
_____ out of 1,000 (1)

Q45 In the BIG BUCKS LOTTERY, the chance of winning a $10 prize is 1%. What is your best guess about how many people would win a $10 prize if 1,000 people each buy a single ticket to BIG BUCKS?
_____ people out of 1,000 (1)

Q46 In the ACME PUBLISHING SWEEPSTAKES, the chance of winning a car is 1 in 1,000. What percent of tickets to ACME PUBLISHING SWEEPSTAKES win a car?
_____ % (1)

Q47 If the chance of getting a disease is 10%, how many people would be expected to get the disease:

- ○ Out of 100? (2) _____
- ○ Out of 1,000? (3) _____

Q48 Timing
First Click (1)
Last Click (2)
Page Submit (3)
Click Count (4)

Page Break

End of Block: PRE-Beliefs/AVOID, and NUM

Start of Block: CCRAT Items

Q49
ABOUT YOU

What is your **height** without shoes?

- Feet (1) _____
- Inches (2) _____

Q50
What is your **weight** without shoes?

- Pounds (lbs) (1) _____

Q51 A drink of alcohol is 1 can or bottle of beer, 1 glass of wine, 1 can or bottle of wine cooler, 1 cocktail, or 1 shot of liquor.

On average, how many **days per week** do you have at least one drink of any alcoholic beverage?

_____

Display This Question:

If If A drink of alcohol is 1 can or bottle of beer, 1 glass of wine, 1 can or bottle of wine cooler, 1 cocktail, or 1 shot of liquor.   During the past 30 days, how many days per week did yo... Text Response Is Not Equal to 0

Q52 On days when you drink, about **how many drinks** do you have on the average?

_____

Page Break

X→ X→

Q53 In your **entire lifetime**, altogether, have you smoked **100 or more cigarettes**?

- Yes (1)
- No (0)
- I don't know (9)

Display This Question:

If In your entire lifetime, altogether, have you smoked 100 or more cigarettes? = Yes

Q54 How old were you when you started smoking cigarettes **on a regular basis**, that is, at least **one cigarette a day for six months or longer**?

▼ I have never smoked cigarettes regularly. (1) ... 54 (50)

Display This Question:

If How old were you when you started smoking cigarettes on a regular basis, that is, at least one ci... , I have never smoked cigarettes regularly. Is Displayed

And How old were you when you started smoking cigarettes on a regular basis, that is, at least one ci... != I have never smoked cigarettes regularly.

X→ X→

Q55 Do you currently smoke cigarettes?

- Yes (1)
- No (0)

Display This Question:

If Do you currently smoke cigarettes? = No

Q56 How old were you when you quit smoking cigarettes completely?

NOTE: If you quit smoking cigarettes completely more than one time, please tell us how old you were the last time you quit smoking completely.

▼ 16 (1) ... 54 (39)

Display This Question:

If How old were you when you started smoking cigarettes on a regular basis, that is, at least one ci... , I have never smoked cigarettes regularly. Is Displayed

And How old were you when you started smoking cigarettes on a regular basis, that is, at least one ci... != I have never smoked cigarettes regularly.

X→ X→

Q57 Thinking back over the years you have smoked regularly, about **how many cigarettes have you usually smoked a day?**

- ○ 1 to 10 cigarettes a day (1)
- ○ 11 to 20 cigarettes a day (2)
- ○ More than 20 cigarettes a day (3)

Page Break

Q58

Vegetables INCLUDE raw, cooked, canned, and frozen vegetables (including beans) and leafy green salads. DO NOT INCLUDE fried vegetables like French fries or fried potatoes.

In the **past 30 days**, about how many **servings per week** of vegetables or leafy green salads did you eat?

- None (1)
- Less than 1 serving per week (2)
- 1-2 servings per week (3)
- 3-4 servings per week (4)
- 5-6 servings per week (5)
- 7-10 servings per week (6)
- More than 10 servings per week (7)

Display This Question:

If Vegetables INCLUDE raw, cooked, canned, and frozen vegetables (including beans) and leafy green s... != None

Q59 In the **past 30 days**, how much did you usually eat in **each serving** of vegetables or leafy green salads?

- ○ 1/2 cup or less (1)
- ○ Between 1/2 cup and 1 1/2 cups (2)
- ○ Between 1 1/2 cups and 3 cups (3)
- ○ Between 3 cups and 5 cups (4)
- ○ More than 5 cups (5)

Page Break

Q60
Moderate physical activities DO NOT cause you to sweat or breathe hard. Some examples include vacuuming, gardening, easy walking for exercise, and so on.

In a typical week, how many **days**, if any, did you do any kind of **moderate** physical activity?

_____

Display This Question:

If If Moderate physical activities DO NOT cause you to sweat or breathe hard. Some examples include va... Text Response Is Not Equal to 0

Q61 During those days, **on average**, about how many **minutes per day** did you do **moderate** physical activities?

_____

Page Break

Q62

Vigorous activities include all activities that DO cause you to sweat or breathe hard. Some examples include racquet sports, basketball, running, fast biking, exercise class, weight lifting, backpacking, swimming, and heavy labor such as shoveling dirt.

In a typical week, how many days, if any, did you do any kind of **vigorous** physical activity?

_____

Display This Question:

If If Vigorous activities include all activities that DO cause you to sweat or breathe hard. Some exam... Text Response Is Not Equal to 0

Q63 During those days, on average, about how many minutes per day did you do **vigorous** physical activities?

_____

Page Break

Q64 To confirm that your responses in the survey are valid, please select disagree for this question.

- ○ Strongly agree (4)
- ○ Agree (5)
- ○ Somewhat agree (6)
- ○ Neither agree nor disagree (7)
- ○ Somewhat disagree (8)
- ○ Disagree (9)
- ○ Strongly disagree (10)

Skip To: End of Block If To confirm that your responses in the survey are valid, please select disagree for this question. != Disagree

Page Break

Q65
During the **past 30 days**, have you taken medications containing aspirin at least 3 times a week, such as:
- Bufferin
- Bayer
- Excedrin
- Other generic form

NOTE: Do NOT include TYLENOL

- Yes (1)
- No (0)
- I Don't Know (9)

Q66
During the **past 30 days**, have you taken medications that **do NOT contain aspirin** at least 3 times a week, such as:
- Advil
- Aleve
- Celebrex
- Ibuprofen
- Motrin
- Naproxen
- Nuprin

NOTE: Do NOT include TYLENOL

- Yes (1)
- No (0)
- I Don't Know (9)

Page Break

Display This Question:

If Are you male or female? = Female

Q67 Do you still have periods?

- Yes (1)
- No (0)

Display This Question:

If Do you still have periods? = No

Q68
When did you have your last period?

- 1 year ago or less (1)
- More than 1 year ago but less than 2 years ago (2)
- 2 years ago or more (3)

Display This Question:

If When did you have your last period? = 2 years ago or more

Q69
During the past 2 years, have you used estrogen, progestin, or other female hormones?

These hormones may be given as hormone pills, oral contraceptives, shots, skin patches, vaginal creams, or as vaginal suppositories.

- ○ Yes (1)
- ○ No (0)

Page Break

End of Block: CCRAT Items

Start of Block: MEN - INT MSG

Q70
Your Colorectal Cancer Risk Summary

*** PLEASE REVIEW THE FOLLOWING INFORMATION CAREFULLY ***

Estimates are not exact. Your risk for developing colorectal cancer during your lifetime may be higher or lower.

Q71 Timing
First Click (1)
Last Click (2)
Page Submit (3)
Click Count (4)

Page Break

Q72

Your Colorectal Cancer Risk Summary

*** PLEASE REVIEW THE FOLLOWING INFORMATION CAREFULLY ***

Although average risk for colorectal cancer is only about 5%, this is just an estimate. An individual's risk of developing cancer can be affected by lifestyle choices. The personalized health messages below are based on your answers to this survey:

[Men Intervention Message]

Q73

	Not at all carefully (1)	Slightly carefully (2)	Somewhat carefully (3)	Moderately carefully (4)	Very carefully (5)
To what extent did you carefully review the information on this page? (Q73_1)	○	○	○	○	○

Q74 Timing
First Click (1)
Last Click (2)
Page Submit (3)
Click Count (4)

End of Block: MEN - INT MSG

Start of Block: MEN - CON MSG

Q75
Your Colorectal Cancer Risk Summary

*** PLEASE REVIEW THE FOLLOWING INFORMATION CAREFULLY ***

Estimates are not exact. Your risk for developing colorectal cancer during your lifetime may be higher or lower.

Q76 Timing
First Click (1)
Last Click (2)
Page Submit (3)
Click Count (4)

Page Break

Q77

Your Colorectal Cancer Risk Summary

*** PLEASE REVIEW THE FOLLOWING INFORMATION CAREFULLY ***

Although the average lifetime risk for colorectal cancer is only about 5%, this is just an estimate. An individual's risk of developing cancer can be affected by lifestyle choices.

Factors that can make your risk of colorectal cancer higher include: Close relatives (parents, brothers, sisters, or children) who have had colorectal cancer History of colorectal polyps Obesity Cigarette smoking Inactive lifestyle

Factors that can lower your risk of colorectal cancer include: Colorectal cancer screening Regular use of aspirin and NSAID's Maintaining a healthy weight Regular, vigorous exercise (all activities that cause sweating and heavy breathing) A diet high in vegetables Hormone replacement therapy use in women

---

Q78

	Not at all carefully (1)	Slightly carefully (2)	Somewhat carefully (3)	Moderately carefully (4)	Very carefully (5)
To what extent did you carefully review the information on this page? (1)	○	○	○	○	○

Q79 Timing
First Click (1)
Last Click (2)
Page Submit (3)
Click Count (4)

End of Block: MEN - CON MSG

Start of Block: WOMEN - INT MSG

Q80
Your Colorectal Cancer Risk Summary

*** PLEASE REVIEW THE FOLLOWING INFORMATION CAREFULLY ***

Estimates are not exact. Your risk for developing colorectal cancer during your lifetime may be higher or lower.

Q81 Timing
First Click (1)
Last Click (2)
Page Submit (3)
Click Count (4)

Page Break

Q82

Your Colorectal Cancer Risk Summary

*** PLEASE REVIEW THE FOLLOWING INFORMATION CAREFULLY ***

Although average risk for colorectal cancer is only about 5%, this is just an estimate. An individual's risk of developing cancer can be affected by lifestyle choices. The personalized health messages below are based on your answers to this survey:

[Women Intervention Message]

Q83

	Not at all carefully (1)	Slightly carefully (2)	Somewhat carefully (3)	Moderately carefully (4)	Very carefully (5)
To what extent did you carefully review the information on this page? (1)	○	○	○	○	○

Q84 Timing
First Click (1)
Last Click (2)
Page Submit (3)
Click Count (4)

End of Block: WOMEN - INT MSG

Start of Block: WOMEN - CON MSG

Q85
Your Colorectal Cancer Risk Summary

*** PLEASE REVIEW THE FOLLOWING INFORMATION CAREFULLY ***

Estimates are not exact. Your risk for developing colorectal cancer during your lifetime may be higher or lower.

Q86 Timing
First Click (1)
Last Click (2)
Page Submit (3)
Click Count (4)

Page Break

Q87

Your Colorectal Cancer Risk Summary

*** PLEASE REVIEW THE FOLLOWING INFORMATION CAREFULLY ***

Although the average lifetime risk for colorectal cancer is only about 5%, this is just an estimate. An individual's risk of developing cancer can be affected by lifestyle choices.

Factors that can make your risk of colorectal cancer higher include: Close relatives (parents, brothers, sisters, or children) who have had colorectal cancer History of colorectal polyps Obesity Cigarette smoking Inactive lifestyle

Factors that can lower your risk of colorectal cancer include: Colorectal cancer screening Regular use of aspirin and NSAID's Maintaining a healthy weight Regular, vigorous exercise (all activities that cause sweating and heavy breathing) A diet high in vegetables Hormone replacement therapy use in women

---

Q88

	Not at all carefully (1)	Slightly carefully (2)	Somewhat carefully (3)	Moderately carefully (4)	Very carefully (5)
To what extent did you carefully review the information on this page? (1)	○	○	○	○	○

Q89 Timing
First Click (1)
Last Click (2)
Page Submit (3)
Click Count (4)

End of Block: WOMEN - CON MSG

Start of Block: POST-RP Group 1

Q90
YOU AND COLON CANCER

On a scale from 0 to 100 %, how would you rate the probability that you will develop colorectal cancer in the future?

_____

Q91

	Very unlikely (1)	Unlikely (2)	Neither likely nor unlikely (3)	Likely (4)	Very likely (5)
How likely is it that you will get colorectal cancer at some point in the future? (Q91)	○	○	○	○	○

Q92

	Much lower (1)	A little lower (2)	The same (3)	A little higher (4)	Much higher (5)
How do you think your chance of developing colorectal cancer in the future compares to the average person of your gender and age? (Q92)	○	○	○	○	○

Q93

	Very low (1)	Low (2)	Neither low nor high (3)	High (4)	Very high (5)
The way I look after my heath means that my odds of getting colorectal cancer in the future are: (Q93)	○	○	○	○	○

End of Block: POST-RP Group 1

Start of Block: POST-RP Group 2

Q94

	Not at all (1)	A little (2)	A moderate amount (3)	A lot (4)	Extremely (5)
How **worried** are you about developing colorectal cancer in the future? (Q94_1)	○	○	○	○	○
How **fearful** are you about developing colorectal cancer in the future? (Q94_2)	○	○	○	○	○
How **nervous** are you about developing colorectal cancer in your lifetime? (Q94_3)	○	○	○	○	○
How **concerned** are you about developing colorectal cancer in your lifetime? (Q94_4)	○	○	○	○	○
How **easy** is it for you to imagine yourself developing colorectal cancer in the future? (Q94_5)	○	○	○	○	○

When you think about colorectal cancer for a moment, to what extent do you feel **fearful**? (Q94_6)	○	○	○	○	○
When you think about colorectal cancer for a moment, to what extent do you feel **worried**? (Q94_7)	○	○	○	○	○
When you think about colorectal cancer for a moment, to what extent do you feel **anxious**? (Q94_8)	○	○	○	○	○

End of Block: POST-RP Group 2

Start of Block: POST-RP Group 3

Q95

	Strongly disagree (1)	Disagree (2)	Neither agree nor disagree (3)	Agree (4)	Strongly agree (5)
When I think carefully about my lifestyle it does seem possible that I could get colorectal cancer. (Q95_1)	○	○	○	○	○
If I look at myself as if I was a doctor, I realize that my behavior puts me at risk of getting cancer. (Q95_2)	○	○	○	○	○
I feel very vulnerable to colorectal cancer. (Q95_3)	○	○	○	○	○
I am confident that I will not get colorectal cancer. (Q95_4)	○	○	○	○	○
I would be lying if I said “There is no chance of me getting colorectal cancer.”	○	○	○	○	○

(Q95_5) My first reaction when I hear of someone getting colorectal cancer is “that could be me someday.” (Q95_6)	○	○	○	○	○

End of Block: POST-RP Group 3

Start of Block: POST-BCA RP

*

Q96
YOU AND BREAST CANCER

On a scale from 0 to 100 %, how would you rate the probability that you will develop BREAST cancer in the future?

_____

X→ X→

Q97

	Very unlikely (1)	Unlikely (2)	Neither likely nor unlikely (3)	Likely (4)	Very likely (5)
How likely is it that you will get BREAST cancer at some point in the future? (Q97)	○	○	○	○	○

X→ X→

Q98

	Much lower (1)	A little lower (2)	The same (3)	A little higher (4)	Much higher (5)
How do you think your chance of developing BREAST cancer in the future compares to the average person of your gender and age? (Q98)	○	○	○	○	○

End of Block: POST-BCA RP

Start of Block: POST-DEM RP

*

Q99
YOU AND DEMENTIA

On a scale from 0 to 100 %, how would you rate the probability that you will develop DEMENTIA in the future?

_____

Q100

	Very unlikely (1)	Unlikely (2)	Neither likely nor unlikely (3)	Likely (4)	Very likely (5)
How likely is it that you will get DEMENTIA at some point in the future? (Q100)	○	○	○	○	○

Q101

	Much lower (1)	A little lower (2)	The same (3)	A little higher (4)	Much higher (5)
How do you think your chance of developing DEMENTIA in the future compares to the average person of your gender and age? (Q101)	○	○	○	○	○

End of Block: POST-DEM RP

Start of Block: POST-BI

Q102
HEALTH BEHAVIORS

	Not at all (1)	A little (2)	A moderate amount (3)	A lot (4)	Extremely (5)
CRCS UTD != 1 How likely are you to get tested for colorectal cancer in the next 6 months? (Q102_1)	○	○	○	○	○
CRCS UTD = 1 How likely are you to get tested for colorectal cancer (when you are due to be tested again)? (Q102_2)	○	○	○	○	○
Are you male or female? = Female *And Mammo UTD != 1* How likely are you to get a mammogram in the next 6 months? (Q102_3)	○	○	○	○	○
Are you male or female? = Female *And Mammo*	○	○	○	○	○

UTD = 1

How likely are you to get a mammogram (when you are due to get a mammogram again? (Q102_4)					
How likely are you to improve your diet in the next 6 months? (Q102_5)	○	○	○	○	○
How likely are you to increase your physical activity in the next 6 months? (Q102_6)	○	○	○	○	○
How likely are you to talk to a doctor about getting tested for colorectal cancer in the next 6 months? (Q102_7)	○	○	○	○	○

Page Break

Q103 Do you have a **healthy diet**?

- YES, I have a healthy diet and I have for MORE than 6 months. (1)
- YES, I have a healthy diet and I have for LESS than 6 months. (2)
- NO, but I intend to improve my diet in the next 30 days. (3)
- NO, but I intend to improve my diet in the next 6 months. (4)
- NO, and I do NOT intend to improve my diet in the next 6 months. (5)

Q104 Are you **physically active**?

- YES, I am physically active and I have been for MORE than 6 months. (1)
- YES, I am physically active and I have been for LESS than 6 months. (2)
- NO, but I intend to increase my physical activity in the next 30 days. (3)
- NO, but I intend to increase my physical activity in the next 6 months. (4)
- NO, and I do NOT intend to increase my physical activity in the next 6 months. (5)

Q105 Do you screen for **colorectal cancer** regularly (as recommended by your healthcare provider)?

- ○ YES, I screen for colorectal cancer regularly, AND I intend to get screened for colorectal cancer when I am due again. (1)
- ○ YES, I screen for colorectal cancer regularly, BUT I do NOT intend to get screened for colorectal cancer when I am due again. (2)
- ○ NO, but I intend to get screened for colorectal cancer in the next 30 days. (3)
- ○ NO, but I intend to get screened for colorectal cancer in the next 6 months. (4)
- ○ NO, and I do NOT intend to get screened for colorectal cancer in the next 6 months. (5)

Display This Question:

If Are you male or female? = Female

Q106 Do you screen for **breast cancer** regularly (as recommended by your healthcare provider)?

- ○ YES, I screen for breast cancer regularly, AND I intend to get screened for breast cancer when I am due again. (1)
- ○ YES, I screen for breast cancer regularly, BUT I do NOT intend to get screened for breast cancer when I am due again. (2)
- ○ NO, but I intend to get screened for breast cancer in the next 30 days. (3)
- ○ NO, but I intend to get screened for breast cancer in the next 6 months. (4)
- ○ NO, and I do NOT intend to get screened for breast cancer in the next 6 months. (5)

End of Block: POST-BI

Start of Block: POST-Beliefs/AVOID

Q107 ATTITUDES AND BELIEFS **How much do you agree or disagree with each of the following statements?**

	Strongly disagree (1)	Disagree (2)	Neither agree nor disagree (3)	Agree (4)	Strongly agree (5)
Cancer is most often caused by a person's behavior or lifestyle. (Q107_1)	○	○	○	○	○
It seems like everything causes cancer. (Q107_2)	○	○	○	○	○
There's not much you can do to lower your chances of getting cancer. (Q107_3)	○	○	○	○	○
There are so many different recommendations about preventing cancer, it's hard to know which ones to follow. (Q107_4)	○	○	○	○	○
I'd rather not know my chance of getting cancer. (Q107_5)	○	○	○	○	○

End of Block: POST-Beliefs/AVOID

Start of Block: Knowledge

Q108 Please indicate whether each of the following either ***increases***, ***decreases***, or ***does not affect*** risk for colorectal cancer:

	Increases Risk (1)	Decreases Risk (2)	Do Not Affect Risk (3)
Being older than 49 years old (>= 50) (Q108_1)	○	○	○
Getting screened for colorectal cancer (Q108_2)	○	○	○
Having a family history of colorectal cancer (Q108_3)	○	○	○
Having a colorectal polyp (Q108_4)	○	○	○
Stress (Q108_5)	○	○	○
Obesity (Q108_6)	○	○	○
Eating more than 3 servings of red meat a week (Q108_7)	○	○	○
Engaging in at least 30 minutes of physical activity a day (Q108_8)	○	○	○
Please select decreases risk for this statement (Q108_attn)	○	○	○
Taking aspirin daily (Q108_9)	○	○	○
Eating less than 5 servings of fruits and vegetables a day (Q108_10)	○	○	○

Smoking (Q108_11)	○	○	○
Drinking more than one serving of alcohol each day (Q108_12)	○	○	○

End of Block: Knowledge

Start of Block: Saliency

Q109 How much do you think health behaviors such as ***diet, exercise, and screening tests*** determine whether or not a person will develop colorectal cancer?

	Not at all (1)	A little (2)	A moderate amount (3)	A lot (4)	Completely (5)
(Q109)	○	○	○	○	○

Q110
Improving my diet would be:

	Strongly disagree (1)	Disagree (2)	Neither agree nor disagree (3)	Agree (4)	Strongly agree (5)
Important (Q110_1)	○	○	○	○	○
Worthless (Q110_2)	○	○	○	○	○
Wise (Q110_3)	○	○	○	○	○
Beneficial (Q110_4)	○	○	○	○	○
Bad/Negative (Q110_5)	○	○	○	○	○

Q111 ***Increasing my physical activity*** would be:

	Strongly disagree (1)	Disagree (2)	Neither agree nor disagree (3)	Agree (4)	Strongly agree (5)
Important (Q111_1)	○	○	○	○	○
Worthless (Q111_2)	○	○	○	○	○
Wise (Q111_3)	○	○	○	○	○
Beneficial (Q111_4)	○	○	○	○	○
Bad/Negative (Q111_5)	○	○	○	○	○

Q112 ***Being tested for colorectal cancer*** would be:

	Strongly disagree (1)	Disagree (2)	Neither agree nor disagree (3)	Agree (4)	Strongly agree (5)
Important (Q112_1)	○	○	○	○	○
Worthless (Q112_2)	○	○	○	○	○
Wise (Q112_3)	○	○	○	○	○
Beneficial (Q112_4)	○	○	○	○	○
Bad/Negative (Q112_5)	○	○	○	○	○

End of Block: Saliency

Start of Block: PERC CONSEQ And PERC Control

Q113 Indicate your level of agreement with the following statements:

	Strongly disagree (1)	Disagree (2)	Neither agree nor disagree (3)	Agree (4)	Strongly agree (5)
Improving my diet would **lower my risk** of getting colorectal cancer. (Q113_1)	○	○	○	○	○
Exercising more would **lower my risk** of getting colorectal cancer. (Q113_2)	○	○	○	○	○
Being tested for colorectal cancer would **lower my risk** of getting it. (Q113_3)	○	○	○	○	○

Q114

	Strongly disagree (1)	Disagree (2)	Neither agree nor disagree (3)	Agree (4)	Strongly agree (5)
There are things I can do to control whether I get colorectal cancer or not. (Q114_1)	○	○	○	○	○
What I do can determine whether I get colorectal cancer or not. (Q114_2)	○	○	○	○	○
My actions will have no effect on whether I get colorectal cancer or not. (Q114_3)	○	○	○	○	○
Nothing I do will affect my colorectal cancer risk. (Q114_4)	○	○	○	○	○

End of Block: PERC CONSEQ And PERC Control

Start of Block: Demographics

X→ X→

Q115
PLEASE TELL US ABOUT YOURSELF

What language do you usually speak at home?

- ○ English (1)
- ○ Spanish (2)
- ○ Other (3)

Q116 What is the highest level of education you completed?

▼ Less than high school or some high school (1) ... Master's degree or higher (6)

Q117 What is your employment status?

▼ Employed full-time (1) ... Disability (6)

Q118 What is your marital status?

▼ Never married (1) ... Widowed (4)

Q119 In general, how would you describe your health?

▼ Excellent (1) ... Poor (5)

Q120 How confident are you filling out medical forms by yourself?

▼ Extremely (1) ... Not at all (5)

Q121 Do you have any kind of health care coverage, including health insurance obtained through employment or purchased directly, as well as government programs like Medicare and Medicaid?

- Yes (1)
- No (0)

Q122 Do you have one person you think of as your personal doctor or healthcare provider?

- Yes (1)
- No (0)

Display This Question:

If Do you have one person you think of as your personal doctor or healthcare provider? = Yes

Q123 What type of health care provider is this person?

▼ Primary or general care physician (1) ... Other (4)

Display This Question:

If Are you male or female? = Female

Q124 Have you ever been told by a doctor or other healthcare provider that you have **breast cancer, ductal carcinoma in situ (DCIS) or lobular carcinoma in situ (LCIS)**?

- Yes (1)
- No (0)

Display This Question:

If Are you male or female? = Female

Q125 Have you ever been told by a doctor or other healthcare provider that you have any **OTHER type of cancer**?

- Yes (1)
- No (0)

Display This Question:

If Are you male or female? = Male

Q126 Have you ever been told by a doctor or other healthcare provider that you have any type of cancer?

- Yes (1)
- No (0)

Display This Question:

If Have you ever been told by a doctor or other healthcare provider that you have any type of cancer? = Yes

Or Have you ever been told by a doctor or other healthcare provider that you have any OTHER type of... = Yes

Q127 What type of cancer were you told you have?

_____

Q128 In which state do you currently reside?

▼ Alabama (1) ... I do not reside in the United States (99)

End of Block: Demographics

Start of Block: Quality/COM HYP/Next Steps

Q129
FINAL QUESTION SET

The information you received about your ***estimated risk (%) of getting colon cancer*** was…?

	1 (1)	2 (2)	3 (3)	4 (4)	5 (5)	
Not Relevant	○	○	○	○	○	Relevant
Not Useful	○	○	○	○	○	Useful
Not Informative	○	○	○	○	○	Informative
Not Credible	○	○	○	○	○	Credible
Not Accurate	○	○	○	○	○	Accurate
Too much information	○	○	○	○	○	Right amount of information
Hard to Understand	○	○	○	○	○	Easy to Understand
Too little information	○	○	○	○	○	Right amount of information

Q130
The information you received about what can ***lower your risk of colon cancer*** was…?

	1 (1)	2 (2)	3 (3)	4 (4)	5 (5)	
Not Relevant	○	○	○	○	○	Relevant
Not Useful	○	○	○	○	○	Useful
Not Informative	○	○	○	○	○	Informative
Not Credible	○	○	○	○	○	Credible
Not Accurate	○	○	○	○	○	Accurate
Too much information	○	○	○	○	○	Right amount of information
Hard to Understand	○	○	○	○	○	Easy to Understand
Too little information	○	○	○	○	○	Right amount of information

Page Break

Q131 **Based on the** colorectal cancer risk information **you received, please indicate your level of interest in the following activities:**

	Not interested at all (1)	Slightly interested (2)	Moderately interested (3)	Very interested (4)	Extremely interested (5)
Getting assistance with goal setting to address identified health risks (Q131_1)	○	○	○	○	○
Discussing your health risk with doctor or healthcare provider (Q131_2)	○	○	○	○	○
Learning about colorectal cancer screening programs in your community (Q131_3)	○	○	○	○	○
Learning about fitness programs (i.e., walking groups) in your community (Q131_4)	○	○	○	○	○
Receiving health risk information related to other conditions	○	○	○	○	○

(i.e., cardiovascular disease) (Q131_5)					
Participating in clinical trials to reduce your risk (Q131_6)	○	○	○	○	○
Learning about nutrition assistance (i.e., diet guidance) in your community (Q131_7)	○	○	○	○	○
Are you male or female? = Female					
Learning about mammography screening programs in your community (Q131_8)	○	○	○	○	○
Participating in health programs in your workplace (Q131_9)	○	○	○	○	○

End of Block: Quality/COM HYP/Next Steps

Start of Block: Goodbye

Q132

The colorectal cancer risk estimate provided to you in this survey was the average lifetime risk for someone your gender living in the United States. If you are interested in learning more about your personal risk, please visit the following website:
https://www.cancer.gov/colorectalcancerrisk/Default.aspx

For more information about colon cancer:
American Cancer Society: https://www.cancer.org/cancer/colon-rectal-cancer.html
Centers for Disease Control and Prevention: https://www.cdc.gov/cancer/colorectal/
Mayo Clinic: http://www.mayoclinic.org/diseases-conditions/colon-cancer/home/ovc-20188216
National Cancer Institute: https://www.cancer.gov/types/colorectal

End of Block: Goodbye