

ABSTRACT

Dissertation Title: “NOTHING TO BE WORRIED ABOUT YET”:
PERCEPTIONS OF COLORECTAL CANCER
AMONG INDIVIDUALS BELOW THE AGE OF
50.

Nora M. Mueller, Doctor of Philosophy, 2019

Directed by: Professor Barbara A. Curbow, Department of
Behavioral and Community Health

National guidelines recommend regular screening for colorectal cancer (CRC) begin at age 50. Recent research however showed rates rising among adults below the age of 50 despite declining overall rates of CRC. Screening guidelines have not been updated to reflect new findings. Younger individuals may not be aware of their CRC risk and providers may be unaware of the need to screen younger patients.

An online survey of individuals between the ages of 24 and 45 was conducted in April and May of 2018 using Amazon© Mechanical Turk. Measures collected included perceived CRC risk and susceptibility, screening knowledge, and understanding of screening results. Analysis I examined these variables by generational cohort. Analysis II randomized participants to receive one of two fictional colonoscopy result reports, the first being the standard of care report provided by a medical center in Maryland and the second a modified report containing a “gist” synthesis of findings. Mixed methods examined participants’ interpretations of these reports. Analysis III randomized participants to receive one of two statements describing trends in the rates of colon cancer to examine participants’ ability to discern false and true information.

Analysis I found Gen-Xers more likely to report higher perceived risk (general cancer and CRC) and severity (general cancer) and be aware of current CRC screening guidelines. Both groups displayed a lack of awareness of CRC screening methods.

Analysis II showed that individuals who received the gist report correctly rated the report as more serious and the importance of follow-up higher than those who received the standard medical report. Analysis III revealed a lack of knowledge among participants to differentiate between correct and incorrect statements regarding colon cancer trends, with participants defaulting to accepting the validity of the statement.

Findings revealed gaps in knowledge of recommended screening activity and available screening methods. Providers should be prepared to discuss available screening options and accurate risk information; in addition, providers should discuss with patients which medical information they read online and remind individuals to take a more critical stance. CRC screening reports that contain a synthesis of findings may help patients plan next steps accordingly.

“NOTHING TO BE WORRIED ABOUT YET”: PERCEPTIONS OF COLORECTAL
CANCER AMONG INDIVIDUALS BELOW THE AGE OF 50.

By

Nora M. Mueller

Dissertation submitted to the Faculty of the Graduate School of the
University of Maryland, College Park, in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
2019

Advisory Committee

Professor Barbara A. Curbow, Chair and Advisor

Associate Professor Faika Zanjani

Assistant Professor Evelyn C. King-Marshall

Professor Robert S. Gold

Associate Professor Xin He, Dean's Representative

© Copyright by
Nora M. Mueller
2019

To Steve, Finn, and Celia,
who are everything

Acknowledgements

I have been very lucky to have had the unwavering support of talented (and patient) women mentors, especially Rani Elwy, Barbara Bokhour, and Barbara Curbow. Very little would have been possible without their encouragement and thoughtful guidance.

I would like to sincerely thank my committee members for their consistently thorough feedback. A special thanks to Faika Zanjani for sticking with me despite moving away and for always returning with doughnuts.

Thank you also to my BCH PhD cohort, who made this an enjoyable process, and the previous cohorts, who were willing to share their experiences and wisdom.

Finally, thanks to Steve for everything (but especially the coffee), and my parents, for always checking in.

Table of Contents

List of Tables and Figures.....	iv
Chapter 1: Introduction.....	1
1.1 Overview.....	1
1.2 Frameworks.....	3
1.3 Justification for Current Study.....	5
1.4 Aims and Hypothesis.....	6
1.5 Definition of terms.....	11
Chapter 2: Literature Review.....	15
2.1 Colorectal Cancer.....	15
2.2 Health Literacy and Cancer Care.....	25
2.3 Fuzzy Trace Theory.....	27
2.4 Mechanical Turk in Research.....	30
2.5 Conclusion.....	33
Chapter 3: Generational Differences in Colorectal Cancer Knowledge.....	34
Abstract.....	34
3.1. Introduction.....	35
3.2. Methods.....	37
3.3. Findings.....	40
3.4. Discussion.....	50
3.5. Conclusion.....	51
Chapter 4: “Nothing too outrageous” v. “I am highly concerned”: Variation in descriptions of medical information when presented differently.....	52
Abstract.....	52
4.1. Introduction.....	53
4.2. Methods.....	56
4.3. Analysis.....	59
4.4. Results.....	60
4.5. Discussion and Conclusion.....	68
Chapter 5: Awareness of Colorectal Cancer Trends Among Individuals Below the Age of 50....	70
Abstract.....	70
5.1. Introduction.....	71
5.2. Methods.....	72
5.3. Findings.....	74
5.4. Discussion.....	78
Chapter 6: Summary.....	80
6.1 Overview of Findings and Implications.....	80
6.3 Strengths and Limitations.....	86
6.4 Future Research Directions.....	87
Appendix A: Methods.....	91
Appendix B: IRB Documentation.....	103
Appendix C: Questionnaire.....	104
Appendix D: MTurk Interface.....	130
References.....	136

List of Tables and Figures

Figure 1A: Adapted Conceptual Model for the Uptake of Colon Cancer Screening.....	4
Figure 1B: Colorectal Cancer Incidence and Mortality Trends	5
Figure 2A: Diagram of the Colon and Rectum	15
Figure 2B: Common Types of Cancer in the United States.....	18
Figure 2C: Colorectal Cancer New Cases and Estimated Deaths.....	18
Table 1.1: Participant Demographics.....	41
Table 1.2: Group Comparisons of Continuous Variables.....	44
Table 1.3: Group Comparison of Categorical Variables.....	45
Table 1.4: Stepwise Linear Regression Models.....	47
Table 2.1: Participant Demographics	61
Table 2.2: Bivariate Analysis of Report Impressions by Report Type.....	63
Table 2.3: Qualitative Responses to "If this colonoscopy report belonged to a loved one, and he or she asked you what it meant, what would you say?.....	65
Table 3.1: Participant Demographics.....	75
Table 3.2: Bivariate Comparison of Groups.....	76
Table 3.3: One-way ANOVA of Statement Received and Response Type.....	77
Table 3.4: Two-Way ANOVA of Statement Received and Correct/Incorrect Response.....	78
Table 3.5: Multiple Linear Regression Assessing Predictors of Confidence in Response	78
Figure A1: Boxplots of Health Literacy by Masters' Qualification.....	97
Figure A2: Boxplots of Numeracy by Masters' Qualification.....	97
Figure A3: Map of participant location created using the latitude and longitude variable	98
Figure A4: Interaction Effects of Statement Received and Correct Identification of Results.....	100
Table A1: Questionnaire constructs and corresponding question numbers.....	102

Chapter 1: Introduction

“Compared with adults born circa 1950, those born circa 1990 have double the risk of colon cancer and quadruple the risk of rectal cancer.” (Rebecca L. Siegel et al., 2017)

1.1 Overview

Increasing colorectal cancer (CRC) screening has been a focus of public health for several years, hinged upon the fact that with regular screening, CRC can be prevented through the removal of precancerous polyps, or treated before spreading (Baron et al., 2008; Holt et al., 2013; Makoul et al., 2009; Sarfaty & Wender, 2007). If detected with Stage I CRC, individuals have a 5-year survival rate of 92%; comparably, the Stage II survival rates are between 62% and 87%, depending on the size and location of tumors, while stage III rates are between 53% and 89%. If detected at Stage IV, CRC has likely metastasized to other parts of the body, and the 5-year survival rate drops to only 11% (ACS, 2017a). The importance of screening and early detection to reduce CRC morbidity and mortality therefore cannot be overstated.

The number of people receiving CRC screenings worldwide has increased, leading to a 3% overall decrease in CRC incidence in the United States between 2001 and 2010 (Edwards BK 2010). However, recent findings from a large retrospective cohort study found rates of colon and rectal cancer in the United States increasing in adults ages 20-29 (2.4%, 3.2%, respectively) and 30-39 (1.3%, 3.2%) from the mid-1980s through 2013. Further findings included increases in rates of colon cancer (1.3%) and rectal cancer (2.3%) for adults age 40-49, and increased rates of colon cancer (0.5%) and rectal cancer (2.3%) in adults ages 50-54 over the same period. This is in opposition to trends in older cohorts; adults age 55 and older experienced a marked decline in rates of CRC in the last three decades (Rebecca L. Siegel et al., 2017).

While some of the increase CRC in younger populations may be due to better detection because of an increase in the use of colonoscopy for screening purposes, researchers posit that recent changes in exposure to carcinogenic risk factors are more likely causes (Edwards et al., 2010a; Siegel, DeSantis, & Jemal, 2014; Rebecca L. Siegel et al., 2017). Factors that have been linked to CRC include excess body weight, high consumption of meat, low consumption of fiber, alcohol and tobacco use, and low physical activity, possibly through increasing inflammation in the bowel and colon, or through more complex genetic interactions (Aune et al., 2011; Hagggar & Boushey, 2009; Johnson et al., 2013; Rebecca L. Siegel et al., 2017).

For the average individual, current guidelines issued by the National Cancer Institute endorse regular screening for CRC beginning at age 50 and continuing until age 75, at intervals determined by family history, comorbidities and previous findings. For individuals with a family history or irritable bowel syndrome, it is recommended that screening begin earlier, as determined by a gastroenterologist. Fecal occult blood test, sigmoidoscopy, colonoscopy, virtual colonoscopy, and DNA stool test are all common tests that vary by length of time it takes to administer, what part of the colon is examined, and the amount of preparation required, among other factors (ACS, 2017a). While the colonoscopy procedure has high sensitivity and specificity, it is often regarded as invasive, risky, or embarrassing by patients (Leggett & Hewett, 2015). Patient preferences and situational context should be accounted for when determining which type of screening method will be used; however, research shows that colonoscopy is the most prescribed screen and considered the most reliable test, resulting in frequent recommendations for colonoscopy screening without proper patient consultation

(Sanguinetti et al., 2015). Subsequently, patient understanding of the colonoscopy procedure is suboptimal, which has important implications for adherence to screening recommendations and follow-up treatment (King-Marshall et al., 2016).

1.2 Frameworks

Conceptual Model

This dissertation uses the Conceptual Model for the Uptake of Colon Cancer Screening (May, Whitman, Varlyguina, Bromley, & Spiegel, 2016) as a springboard for examining patient factors impacting knowledge of CRC screening guidelines and understanding of screening results (Figure 1). This conceptual model is based on a 2002 report by the Institute of Medicine, and includes patient characteristics, provider practices, and system-level factors that predict or act as barriers to screening (IOM, 2003). This model has been adapted to fit the scope of this study and expanded to include factors that facilitate or bar understanding of screening guidelines and results. Included in the analysis are patient variables found in the model, which have been underexplored in previous research, as well as new patient variables that have been shown to be significant in previous research by the research team. These variables are shown in **Figure 1A**, with starred variables indicating inclusion in this study.

Theory

This study is further informed by a **Health Literacy (HL)** and **Numeracy** framework, as well as **Fuzzy Trace Theory (FTT)**. Health literacy, or the ability of patients and health professionals to provide, communicate, understand and process health information, is a complex issue that is not well understood. Numeracy, which is a person's ability to

understand and work with numbers, is considered a part of health literacy, as the variables are associated with negative health behaviors (Kiechle, Bailey, Hedlund, Viera, & Sheridan, 2015; Yee & Simon, 2014), and yet the impact of HL, and especially of numeracy, on health outcomes remains unclear (Berkman et al., 2011).

Fuzzy Trace Theory (FTT) is a psycholinguistic theory developed by Valeria Reyna and Charles Brainerd and has been used to examine medical decision-making and information processing (Reyna, 2008, 2012; Reyna & Brainerd, 1995). The theory contains two main constructs, **verbatim representations** and **gist representations** (usually shortened to verbatim and gist). Individuals process new information using one

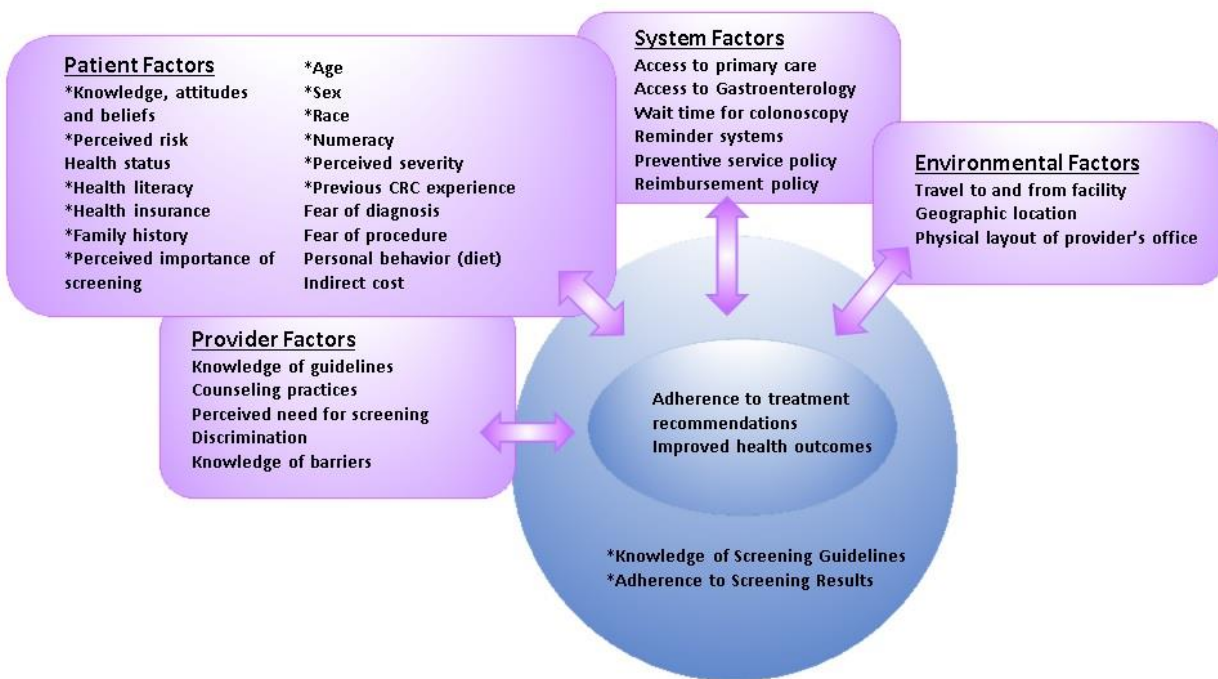


Figure 1A: Conceptual Model. Adapted from May FB, Whitman CB, Bromley EG, Spiegel DM (2016).

of these two representations: verbatim, which is a literal and “surface-level” memory of the information, or gist, which is an affective, meaning-based memory. Gist representations are more likely to be remembered, and can be recalled and used to interpret new information, unlike verbatim representations, which are usually quickly

forgotten and offer little assistance in decision-making (Reyna, Nelson, Han, & Dieckmann, 2009). Based on previous work by the University of Maryland Department of Behavioral and Community Health Colorectal Cancer Research Group, led by Dr. Barbara Curbow, this study proposes to further examine the relationship between HL, numeracy, and individuals' ability to form gist interpretations of medical information.

1.3 Justification for Current Study

Figure 1B displays increases in CRC incidence and mortality among individuals below the current recommended age of screening initiation in the United States. A recent projection predicted continued increases in CRC incidence rates among adults under the

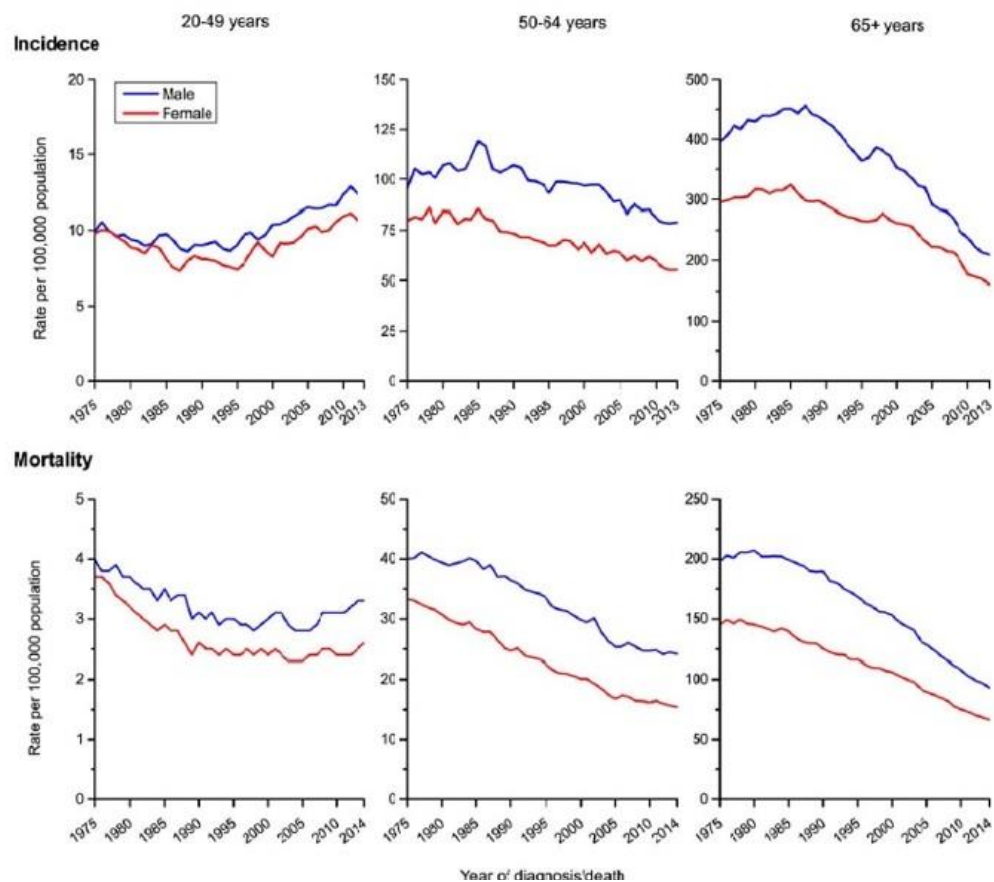


Figure 1B: Colorectal Cancer Incidence and Mortality Trends by Age and Sex, United States, 1975-2014 (Sigel, et al. 2017).

age of 55 through 2040 (Araghi et al., 2018). When CRC is detected individuals below the age of 50, it is usually found at an advanced stage and mortality rates are higher (Campos, 2017). It is therefore critical to begin discussing CRC in younger populations and possible actions to optimally prevent this pathology. For this to occur, an understanding of how individuals in this population conceptualize CRC is vital. Furthermore, it is important that these individuals are able to proceed with screening and are provided them with appropriate medical information throughout the screening process. To begin to address these issues, the analyses within this dissertation examined how individuals below the current recommended age of regular CRC screening perceive CRC risk and severity, as well as the importance of CRC screening. Furthermore, I examined how these individuals understand results from a CRC screening report when presented to them, and if small alterations to this report can lead to a better understanding of findings. Finally, I tested individuals' awareness of current CRC trends, their ability to distinguish between false and true information regarding these trends, and the factors associated with certainty of the accuracy of their response.

1.4 Aims and Hypothesis

This study recruited a sample of individuals below the current recommended age of CRC screening using Mechanical Turk, an Amazon.com subsidiary company, to examine differences in knowledge of CRC screening and understanding of colonoscopy screening results. One aim was to examine differences in CRC knowledge and perceptions of risk and severity between generational cohorts, that is, individuals classified as Millennials and those belonging to Generation X. The Pew Research Center, acknowledging that generational groupings are imprecise, defines Millennials as individuals who were born

somewhere between the early 1980s and mid- 1990s; for the purposes of this study, I included older Millennials, or individuals who were between the ages of 25 and 35 at the time of data collection. Generation X is the cohort prior to Millennials, and birth years for GenXers generally range from the late 1960s through the early 1980s; for this study, I included younger GenXers, or individuals who were between the ages of 36 and 45 at data collection (Pew Research Center, 2014). These age ranges were chosen to examine perceptions of susceptibility and understanding of screening among individuals who currently are not of age of recommended CRC screening, as CRC incidence is increasing for this population. The two age ranges allowed for a comparison between those who are approaching the age of currently recommended regular CRC screening (36-45 years of age), compared with those who are farther removed from this responsibility (25-35 years of age).

Variables bolded in **Figure 1A** were examined to discern variation between and within generational cohorts, as were their relationship with the dependent variables (knowledge of CRC screening, understanding of screening results). Individual level variables that were included in the original Conceptual Model for the Uptake of Colon Cancer Screening, but were not included here, are fear of CRC diagnosis, fear of the colonoscopy procedure, diet and cost, as these were considered to be either not yet applicable to the age groups I examined (fear of CRC, fear of procedure, indirect cost of procedure) or outside of the scope of the current survey (diet). New additions to the individual-level factors were age (and generational cohort), race, numeracy and perceived severity of CRC, which are variables of interest based in the literature. The below aims and hypotheses guided this work.

Aim 1

Compare differences in perceived risk to CRC and severity of CRC diagnosis between age groups.

H1: GenXers report higher levels of perceived risk to CRC, compared with Millennials.

H2: Millennials are more likely to think a CRC diagnosis will result in death, compared with GenXers.

Theory/Evidence-based Justification: Recent research has found rates of colorectal cancer increasing in adults below the age of 54 (Rebecca L. Siegel et al., 2017); however, national guidelines still set the average age of CRC screening commencement at 50, with variations based on family history and lifestyle factors (ACS, 2017a). This may lead to the perception that CRC is a disease related to aging, and younger individuals may not be aware of the risk of CRC (Rabin, 2017). Furthermore, inadequate health literacy and low numeracy is associated with higher levels of perceived risk (Reyna et al., 2009): I therefore posit that Millennials are less aware of factors surrounding CRC and therefore overestimate the severity of a diagnosis. These hypotheses will be tested using Questions 2-13 (health literacy and numeracy), Question 33 (perceived susceptibility to CRC) and Question 34 (perceived severity of CRC diagnosis) of the questionnaire.

Aim 2

Assess knowledge of CRC screening methods and guidelines between age groups.

H3: GenXers score higher on measures of knowledge of CRC screening, compared with Millennials

Theory/Evidence-based Justification: Adults between the ages of 36-45 are approaching the age at which guidelines suggest regular treatments should begin. Individuals with a family history of CRC are recommended to begin screening at age 40, while those without a family history of CRC are counseled to begin screening at age 50.

Conversations with providers about CRC family history, lifestyle factors, and screening preferences optimally occur early in the patient-provider relationship to determine the optimal age to begin regular screening. Low health literacy and numeracy have been shown to be barriers to understanding medical recommendations and information (Seurer & Vogt, 2013). African Americans shown to be less likely to undergo CRC screening or diagnostics, and suffer from higher rates of CRC incidence and mortality, and at a younger age, than Caucasians or Asians (R. Williams et al., 2016). Research suggests that adequate health literacy may serve as a buffer (Reyna et al., 2009). These hypotheses will be tested using Question 14 and 18 of the questionnaire (Knowledge of CRC Screening) and Questions 2-5 (Perceived Health Literacy).

Aim 3

Assess participants' relationship with a provider and the impact the relationship with a provider has on CRC screening knowledge and perceptions of susceptibility

H4: GenXers more often report having a provider whom they see regularly, compared with Millennials.

H5: Participants with an established relationship with a provider display more CRC knowledge compared with participants without an established relationship.

Theory/Evidence-based Justification: The patient-provider relationship has been shown to impact numerous facets of healthcare (Ha & Longnecker, 2010; Zolnierek & Dimatteo, 2009), including the likelihood of undergoing CRC screening: Research showed that patients who felt they had enough time with a provider and received sufficient information about the procedure were more likely to receive CRC screening (Carcaise-Edinboro & Bradley, 2008). Similarly, patients with a more established relationship with a provider are more likely to discuss their CRC risk and when to begin screening. Thus, I posit that older participants, having had more time in to engage in the medical system, are

more likely to have an established relationship with a medical provider. This hypothesis will be examined using questions 14 and 18 (CRC screening knowledge) and 74 of the questionnaire (Provider Relationship).

Aim 4

Assess whether participants who receive a colonoscopy report formatted to contain Gist information report different perceptions about the report than participants who receive a standard colonoscopy report.

H6: Participants who receive Report 1 (verbatim) provide lower scores of perceived seriousness, compared with participants who receive Report 2.

H7: Participants who receive Report 1 (verbatim) rate the importance of follow-up lower than participants who receive Report 2.

H8: Participants who received Report 2 (gist) are more likely to agree that there is a plan of care in place for the patient, compared with participants who receive report 1.

Exploratory: How would patients describe the reports to their loved ones, and how does this differ by report type?

Theory/Evidence-based Justification: Report 2 presented the participant with “gist” information, i.e. a synthesis of pertinent information and follow-up steps that was designed to required less interpretation and placed less cognitive burden on the patient. Fuzzy-Trace Theory (FTT) guided the design of Report 2 (Reyna, 2008, 2012; S. G. Smith et al., 2015). Information presented in medical jargon has been shown to cause confusion and anxiety among patients (Herber, Gies, Schwappach, Thürmann, & Wilm, 2014; Schnitzler et al., 2017). These hypotheses will be tested using Question 23 of the report, as well as Question 25 (If this report belong to a loved one, and he or she asked you what it meant, what would you say?).

Aim 5

H9: When presented with a false statement about colon cancer trends, participants with low HL are more likely to believe it is true, compared with those with high HL

1.5 Definition of terms

Colorectal Cancer (CRC) Colorectal cancer is any cancer that begins in the colon or rectum. These cancers are often grouped together because they share similar features and similar methods of screening, diagnosis and treatment. Most colorectal cancers begin as a growth on the inner lining of the colon or rectum, called a polyp.

Colonoscopy An outpatient procedure to examine the colon and rectum for precancerous or cancerous polyps or lesion, or to monitor existing conditions. During a colonoscopy, a small, flexible tube with a camera at the end is inserted through the colon to allow providers to see the inside. Any polyps that are found can be removed and retrieved for possible biopsy. The procedure itself takes about 30 minutes to complete. However, preparation for the procedure usually requires fasting or a clear diet for one or more days before, in addition to the consumption of a laxative in either pill or liquid form.

Colonoscopies are usually performed by a gastroenterologist and require sedation.

Complications are rare, but include perforation, bleeding and pain (ACS, 2017a).

Health Literacy (HL) One of the earliest definitions of HL described it as a patient's ability to apply literacy skills to health related materials like prescriptions, appointment cards, medicine labels, and directions for follow-up care (Parker, Baker, Williams, & Nurss, 1995). Since then, health literacy has had a variety of definitions (Nutbeam, 2000; M. S. Wolf et al., 2012), but at their most simple, these define HL as the ability of individuals to obtain, process, and understand health information. Definitions like these are somewhat controversial, as they seem to place the burden of obtaining and understanding health information on the patient. Some researchers therefore argue that HL is actually the purview of health providers and health systems, in that they are

responsible for ensuring the availability of health materials, proper communication of information, and access to services which allows for optimal HL in the patient (Lambert et al., 2014; R. Rudd, AT, & D, 2012; R. E. Rudd, 2013). The Calgary Charter on Health Literacy offers a definition of HL that attempts to incorporate the role of the health professional:

Health literacy allows the public and personnel working in all health-related contexts to find, understand, evaluate, communicate, and use information. Health literacy is the use of a wide range of skills that improve the ability of people to act on information in order to live healthier lives. These skills include reading, writing, listening, speaking, numeracy, and critical analysis, as well as communication and interaction skills (Coleman, Kurtz-Rossi, & McKinney, 2009).

HL is measured through either skill-based assessment or self-report. When asked about existing health literacy measures, 88% of those who work with these tools stated that they are inadequate and do not capture the complexity of health literacy; 90% stated that new tools to measure health literacy are needed (Pleasant, 2014).

Numeracy Montori and Rothman (2007) define numeracy as follows:

The specific aspect of literacy that involves solving problems requiring understanding and use of quantitative information. Skills include understanding basic calculations, time and money, measurement, estimation, logic, and performing multistep operations. Most importantly, numeracy also involves the ability to infer what mathematic concepts need to be applied when interpreting specific situations.

Even though numeracy is often seen as a part of literacy and health literacy, only one measure exists that combines the two into a single score (The Test of Functional Health Literacy in Adults, or TOFHLA). Numeracy generally lags behind health literacy: national surveys indicated that approximately 36% of American adults have inadequate numeracy skills (Reyna et al., 2009). While health literacy is correlated with educational

level, no such association exists for numeracy (Rothman, Montori, Cherrington, & Pignone, 2008).

Fuzzy Trace Theory (FTT) Fuzzy-trace theory is a dual-process model of memory, reasoning, judgment, and decision making that contrasts with traditional memory approaches in that it states that memorization does not equal knowledge. Rather, the theory introduces the construct of “Gist representation”, which is the titular fuzzy trace (Blalock & Reyna, 2016).

Gist This is a main construct of Fuzzy Trace Theory, first proposed by Valerie Reyna and Charles Brainerd (Reyna & Brainerd, 1995). It is also called gist representation or gist memory, and is defined as the bottom-line, summative meaning. Gist memories can be used to inform new situations, unlike verbatim memory. Gist stands in opposition to verbatim.

Verbatim This is the second main construct of Fuzzy Trace Theory, and defined as the word-for-word representation of a memory. It is considered more superficial than Gist, is more easily forgotten and does not extend to new learning. Verbatim is also called verbatim memory or verbatim representation.

Perceived Risk A subjective assessment of risk of developing a health problem. This is a central construct of the Health Belief Model, which states that individuals who perceive themselves to be at high risk of developing a health problem are more likely to engage in behaviors to reduce their risk, compared with individuals who perceive themselves at lower risk.

Perceived Severity This is another central construct of the Health Belief Model and

refers to the degree people deem a particular disease or condition serious. This includes a weighing of the cost and consequences of treating or not treating the disease.

Chapter 2: Literature Review

2.1 Colorectal Cancer

2.1.1 Overview

Colorectal cancer (CRC) is the name given to cancers in any of the four parts of the **colon** (the **ascending colon**, including the cecum, the **transverse colon**, the **descending colon**,

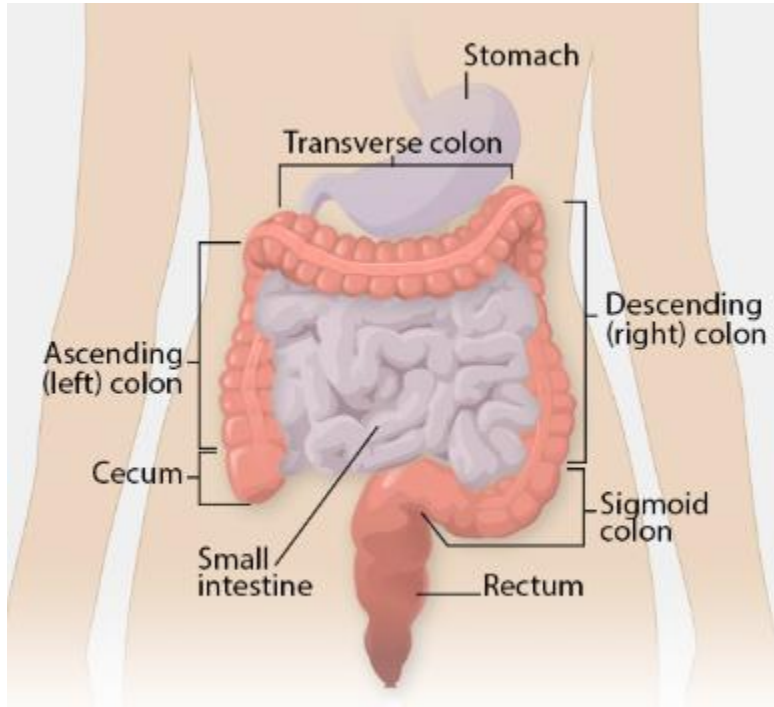


Figure 2A: Diagram of the colon and rectum. From Centers for Disease Control:
https://www.cdc.gov/cancer/colorectal/basic_info/what-is-colorectal-cancer.htm

CRC often being called bowel cancer. Anal cancers, despite their anatomical proximity, are not classified as CRC because they originate from different cell types and do not develop in ways similar to CRC (ACS, 2017a, 2017b).

CRC begins with the formation of **pre-cancerous polyps** in the lining of the colon or rectum. When cancer forms within a polyp, it can begin to grow into the walls of the colon or rectum, and from there spread to nearby lymph nodes and more distant parts of the body. Not all polyps, however, are precancerous, and not all precancerous polyps

and the **sigmoid colon**; see **Figure 2A** for reference) or **rectum**. These cancers are grouped together because of shared etiology and attributes. *Colon* is another name for the large intestine, colloquially referred to as *the bowel* (or, in combination with the small intestine, *the bowels*), which leads to

develop into cancer. The most common type of polyps are **adenomatous polyps**, or adenomas. Approximately 10% of these adenomas develop into **adenocarcinoma**, a type of CRC that accounts for 96% of all cases (ACS, 2017a).

2.1.2 Risk of CRC

The lifetime risk of CRC is approximately 5% (Sag, Selcukbiricik, & Mandel, 2016)c. Worldwide, colorectal cancer is the fourth leading cause of death from cancer, and incidence rates are projected to increase (Subramanian et al., 2016). The American Cancer Society (ACS) describes an increase in the global incidence from 1992 to 2005 among adults between 20 and 49 years, specifically a 3.5% increase per years among men and 2.9% per year in women. In the United States, the ACS identified a consistent incidence increase from 1998 to 2007 (Rebecca L. Siegel et al., 2017), and similar trends are seen worldwide (2007).

2.1.3 Risk Factors

Several risk factors for CRC have been identified, most notably familial risk. Heritable causes are estimated to account for anywhere between 5% and 30% of colorectal cancers. Most of these cases do not belong to a known inherited syndrome (Campos, 2017), meaning that the genetic link to family history and development of CRC or pre-cancerous polyps is not established. An individual's risk of CRC increases two to three times with the existence of a first-degree relative with CRC, compared to those without relatives with CRC. This risk increases as the number of relatives with CRC increase. Furthermore, an individual with a history of CRC themselves has an increased risk of further CRC incidence (Campos, 2017; Johnson et al., 2013).

While a family history of colorectal cancer or inflammatory bowel disease is one significant risk factor for CRC, lifestyle variables likely interact with these to account for many other risk and protective factors (Johnson et al., 2013) and are the focus of most behavioral interventions (Edwards et al., 2010a). The most cited life-style related risk factors include obesity, cigarette smoking, heavy alcohol use, and consumption of red meat; protective factors include increased levels of fruit and vegetable consumption and physical activity (Johnson et al., 2013). One study found that switching rural South Africans from their traditional high fiber, low-fat diet to a western-style diet high in fats and low in fiber lead to inflammation in the colonic mucosa in about two weeks (O'Keefe et al., 2015). This supports a classic study from 1999, which found that the risk of CRC increased sharply within one generation of families moving from Japan to the United States, likely because of an increase in the consumption of red meat (Marchand, 1999). However, more recent studies have challenged the idea of a Western diet as fundamental to CRC, especially in younger populations, and instead call for more thorough investigations of genetic causes (Deen, Silva, Deen, & Chandrasinghe, 2016).

2.1.4 Burden of CRC

In 2002, colorectal cancer comprised 9.4% of the global cancer burden in both sexes and was most frequent in North America, Australia, New Zealand, and parts of Europe, resulting in a widespread belief that colorectal cancer is disease of the Western lifestyle

(2007). In the early 1950s, CRC was a leading cause of cancer death in the United States (Siegel et al., 2014). In 2016, CRC ranked as the second leading cause of cancer

Common Types of Cancer	Estimated New Cases 2016	Estimated Deaths 2016
1. Breast Cancer (Female)	246,660	40,450
2. Lung and Bronchus Cancer	224,390	158,080
3. Prostate Cancer	180,890	26,120
4. Colon and Rectum Cancer	134,490	49,190
5. Bladder Cancer	76,960	16,390
6. Melanoma of the Skin	76,380	10,130
7. Non-Hodgkin Lymphoma	72,580	20,150
8. Thyroid Cancer	64,300	1,980
9. Kidney and Renal Pelvis Cancer	62,700	14,240
10. Leukemia	60,140	24,400

Figure 2B: SEER 2016: Common Types of Cancer in the United States

deaths behind lung and bronchus cancer, and fourth most common cancer diagnosed (Figure 3A). In the same year, CRC was estimated to account for just under 135,000 new cancer cases and approximately 50,000 of all cancer deaths in the United States (Figure 4A). There has been a steady overall decline over the past decades in both CRC incidence and mortality, most recently at a rate of approximately 3% per year from 2004-2013. This has been attributed to monumental public health efforts, including screening, detection, and treatment, as well changes in lifestyle factors such as a general decline in smoking and alcohol consumption (Edwards et al., 2010b).

However, this decline is not consistent across age-groups: Sigel, et. al (2017) analyzed colorectal cancer trends in SEER data from 1974 through 2013 and found that while, as expected, rates declined in individuals age 55 and older, the rates of colon cancer incidence increased by 2.4% per year in adults age 20-29, and by 1% in adults

Estimated New Cases in 2016	134,490
% of All New Cancer Cases	8.0%
Estimated Deaths in 2016	49,190
% of All Cancer Deaths	8.3%

Figure 2C: Seer 2016: Colorectal Cancer New Cases and Estimated Deaths

age 30-39, between 1985 and 2013. Furthermore, around 1995, rates among individuals age 40-49 and those 50-54, which had previously been declining, began to increase at a rate of 1.3% and .5%, respectively. Rectal cancer rates increased even more steeply; from 1974-2013, rectal cancer increased by 3.2% per year in adults age 20-29, and, beginning in 1980, at the same rate for adults age 30-39. Adults age 40-49 and 50-54 experienced a rise in rates of 2.3%, beginning in the 1990s. The authors attribute these rising rates to changes in behavioral factors, such as increased sedentary lifestyles, poor diet and obesity.

Furthermore, the overall decline in CRC is not uniformly distributed across populations and reflect larger social inequity in the US. Research shows that the burden of CRC is greater among African Americans and those of lower socioeconomic status. This is thought to be the result of several factors: behavioral risk factors that result in earlier development of CRC, limited knowledge about the importance of regular screening, a lack of access to preventive services, difficulty taking time off of work for medical visits, or cultural differences in how testing is viewed (Clouston et al., 2017).

2.1.5 Financial Cost of CRC

Patients in the US face staggering costs for medical care. Cancer care may be especially costly, as treatments can be lengthy and require the consultation of numerous specialists. The AHRQ estimated that the direct medical costs for cancer in the US in 2014 were \$87.8 billion, and the cost of CRC alone was previously estimated to be around \$6 billion annually (AHRQ, 2016; Redaelli, Cranor, Okano, & Reese, 2003).

A case study of a Medicare patient receiving treatment for Stage IIB CRC found that the total cost of treatment over four months was \$124,057, of which the patient paid

approximately \$8573. This expense covered treatment, including surgery and adjuvant chemotherapy, but did not include follow-up care and out-of-pocket costs for additional screening (ACS, 2017c). It furthermore did not include the indirect costs of cancer care, such as time missed from work, transportation to and from the medical facilities, the worry and stress associated with cancer diagnoses and treatment, the burden on friends and family, and the impact on overall health.

A cost-effectiveness analysis for the five most common CRC screening methods found that the cost of any of the methods, when compared to no screening at all, was acceptable by the standards of an industrialized nation, as the number of life-years saved justified the cost. Yet when individual screening methods were compared against each other, no optimal screen emerged in terms of cost (Lansdorp-Vogelaar, Knudsen, & Brenner, 2010).

2.1.6 Screening

If found early, the 5-year survival rate is over 90%; however, only about 35% of CRC is diagnosed at Stage 1, and as described above, diagnosis is often at a later stage for younger individuals (Campos, 2017; Taggarshe, Rehil, Sharma, Flynn, & Damadi, 2013). For individuals of average CRC risk, the American Cancer Society recommends screening by colonoscopy every ten years beginning at age 50, or screening with a flexible sigmoidoscopy or barium enema every five years, also beginning at age 50 (ACS, 2017a). However, as early as 2011 calls have been made to lower this to age 40 (D. M. Davis et al., 2011)

Individuals considered to be at higher than average risk for CRC are those with a family or personal history of CRC or polyps, or a personal history of chronic

inflammatory bowel disease, namely ulcerative colitis or Crohn's disease. The most common symptoms of CRC are blood in stool, abdominal pain, weight loss, alteration in bowel habit, mucus in stool, a feeling that the bowel is not empty, and tiredness (Yardley, Glover, & Allen-Mersh, 2000). Individuals with these risk factors or symptoms are advised to speak with a gastroenterologist to determine an individualized screening schedule (ASGE, 2014; Levin et al., 2008).

Black males are disproportionately affected by CRC, leading to recommendations to start screening earlier and conduct it more frequently in this population. The American Society for Gastrointestinal Endoscopy (ASGE) recommends that African Americans begin screening at age 45, as both incidence and mortality are higher among African Americans than any other population (ASGE, 2014)

As of 2015, at least 40% of individuals who were of age to begin CRC screening were not concordant with guidelines, meaning that they had either not yet initiated screening or were not getting screened at regular intervals. Further research found that a provider recommendation to undergo screening was the most influential factor in determining whether or not someone has received screening for CRC (Alberti, Garcia, Coelho, De Lima, & Petroianu, 2015).

Several CRC screening methods exist. In the United States, the five most common screens are: 1. Fecal Occult Blood test (FOBT), which is an at-home test that checks for blood in feces; 2. Stool DNA test, which is an at-home test that detects certain genetic changes associated with colon cancer; 3. Barium enema, which is an X-ray exam that can detect abnormalities in the large intestine; 4. Flexible sigmoidoscopy, which consists of a flexible tube inserted into the anus to examine the rectum and lower colon; and 5.

Colonoscopy, which uses a similar tube to examine the rectum and entire colon, and is often considered the gold standard for detecting and treating CRC because of its ability to both detect and treat CRC through the immediate removal of precancerous polyps (ACS, 2017a).

A method not yet prevalent in the United States but part of recommended regular screening in other developed countries is the Fecal Immunochemical Test (FIT). The one-sample FIT is easier to administer than the traditional FOBT, which requires three samples, and as a result increases adherence to screening steps (Hassan et al., 2012; Issaka, Avila, Whitaker, Bent, & Somsouk, 2019). FIT was also demonstrated to have fewer false negatives compared to FOBT (Mousavinezhad, Majdzadeh, Akbari Sari, Delavari, & Mohtasham, 2016) and exhibit moderate sensitivity, high specificity and high overall diagnostic accuracy (Lee, Liles, Bent, Levin, & Corley, 2014).

2.1.7 CRC Screening in Younger Populations

The question of whether or not young people are being overlooked in screening has been raised and should be considered. 60% of young patients are diagnosed with stage 3 or 4, compared with patients over the age of 50, who are mostly diagnosed at stage 1. Most younger patients had been symptomatic for over six months at the time of diagnosis (Taggarshe et al., 2013). As a result, suggestions for educational and preventive interventions focusing on younger cohort have been made. Additionally, providers are cautioned to adopt a more suspicious attitude towards CRC symptoms in younger populations (Campos, 2017). Lowering the screening age has been proposed, though implications of this, such as cost and survival rates, have not yet been adequately assessed and there currently is no consensus on this recommendation (Deen et al., 2016).

2.1.8 Colonoscopy

According to the World Gastroenterology Association (WGA) (2007), CRC screening, compared with screening for other cancers, is particularly challenging, as reflected in current low screening rates in most countries where there is a high risk for colorectal cancer. Colorectal cancer screening is complex and presents with multiple points at which decisions are required. To begin, there are multiple choices available for screening, each requiring a different level of involvement on the part of the patient. Some require requires sedation and a partner or caregiver (for example, for a colonoscopy procedure, the patient is required to bring along a person responsible for transporting them home). Further steps involve patient-provider conversations regarding the availability and feasibility of screening, patient acceptance of the method, financial coverage, overcoming barriers such as fear and discomfort, and appropriate follow-up. The WGA states that for screening programs to be successful, these steps must occur along a continuum, with failure at any point detrimental to the screening process.

Colonoscopy remains the most widely prescribed and most known CRC screen (Sanguinetti et al., 2015). Research has identified several barriers to getting a colonoscopy, including cost, access to health care, communication by providers, low education and income, fear and embarrassment, inability to take time off work, and being unable to find someone to accompany the patient to the procedure (B. Curbow, King-Marshall, Mueller, Sultan, & George, under review; B. A. Curbow et al., 2015; Jones, Devers, Kuzel, & Woolf, 2010; M. S. Wolf, Baker, & Makoul, 2007). Patient with inadequate health literacy are especially prone to encountering these barriers, and face additional obstacles such as confusion during medical consultations, inability to complete

medical forms or embarrassment during clinical encounters, all of which can lead to medical non-compliance (M. S. Wolf et al., 2012).

Most CRC diagnoses are after evaluation by colonoscopy, and colonoscopy can be viewed as a pivotal event in the process of preventing, detecting, and treating colorectal cancer. If caught early through screening colonoscopy, colorectal cancer can be prevented through the removal of precancerous polyps or detected at an early, easily treatable stage (ACS, 2017a). Because it allows for screening, diagnosis and treatment (through the removal of polyps) at the same time, colonoscopy is the most widely recommended screen for CRC. Research that examined provider discussions about CRC screening methods with patients found that providers consider colonoscopy to be the most significant test for CRC screening and diagnosis, and discuss it most with eligible patients (84% of the time, compared with FOBT at 49.4% of the time, and sigmoidoscopy at 34.1% of the time) (M. S. Wolf et al., 2007). This is problematic because numerous barriers to colonoscopy exist, and presenting other, less invasive CRC screening methods to patients may result in increased adherence to screening recommendations (Basch, Basch, Zybert, & Wolf, 2016; Klabunde et al., 2005). Presenting other methods may also result in decreasing inequalities in CRC mortality, as barriers to colonoscopy are compounded for the African American population (Atkin et al., 2010; Clouston et al., 2017). However, one study found that conversations about numerous CRC screening options left patients confused, and resulted in less adherence to screening guidelines when compared with individuals who only discussed one option (Jones, Vernon, & Woolf, 2010). This implies that there is not only a need to present patients with the multiple options available to them, but to also optimize how information

is presented and to provide continued counseling through the decision-making process.

2.2 Health Literacy and Cancer Care

The Centers for Disease Control and Prevention (CDC), Health and Human Services (HHS) and the Institute of Medicine (IOM) define health literacy as the ability to obtain, process, and understand basic health information and services so as to make appropriate health decisions {CDC, 2013}.

Health literacy levels have been associated with patient understanding of screening procedures (Cho, Plunkett, Wolf, Simon, & Grobman, 2007), and research indicates that health literacy is a critical factor in communication across cancer care (T. C. Davis, Williams, Marin, Parker, & Glass, 2002). Health literacy has been shown to be associated with health knowledge, adherence to medication regimen, and treatment guidelines (Gaj Levra, Cuniberti, Rava, Vietti, & Sciascia, 2012; Miller, 2016; Muir et al., 2006; Murphy et al., 2010; Rust & Davis, 2011), and numerous interventions have succeeded in increasing health literacy among participants (Muir et al., 2006; Ntiri & Stewart, 2009; Whitley, Smith, & Vaillancourt, 2013).

However, the mechanisms through which health literacy impacts health outcomes are not yet defined (Al Sayah, Majumdar, Williams, Robertson, & Johnson, 2013). While some propose that health literacy acts to improve health outcomes through increasing adherence to provider recommendations, others see this view as too narrow and argue that health literacy is fundamental in the empowerment of patients, for example by increasing individual ability to overcome functional barriers to accessing health care (Nutbeam, 2000). In such a view, increasing health literacy has implications not only for improved health care and outcomes, but for improvements in other areas requiring critical

thinking and decision making, such as cognitive information representation.

Nutbeam (2000) identified three hierarchical levels of health literacy through which individuals progress; 1. Basic or functional health literacy, which are everyday reading and writing skills; 2. Communicative or interactive literacy, which interacts with social context and allows individuals to extract personal meaning out of communication; and 3. Critical literacy, which, again combined with social skills, allows for the use of critical thinking and analysis to exert greater control over life and health. These classifications, rather than being individual endpoints, lie on a spectrum. Individuals move along the spectrum through cognitive development and exposure to different messages, though this movement is mediated by personal and social skills (Nutbeam, 2000). Patients on the lower end of the health literacy spectrum report poorer health status, have less understanding about medical conditions and treatment, may have increased hospitalization rates, and have poorer performance on healthcare tasks (M. V. Williams, Davis, Parker, & Weiss, 2002). Low health literacy may limit patients' understanding of cancer screenings, symptoms, staging, and risks and benefits of treatment options (Cutilli & Bennett, 2009), and compared to patients with high health literacy, those with low health literacy take a less active role in health decision-making (Adams, Smith, & Ruffin, 2001). While patients with low health literacy have reported being familiar with CRC and CRC screenings, research indicates they may not understand the benefits of early detection or the concept of cancer prevention (T. C. Davis et al., 2001). Low or limited health literacy skills have also been found to be associated with less knowledge about CRC and CRC screening and with more reported barriers to completing FOBT and colonoscopy (N. B. Peterson, Dwyer, Mulvaney,

Dietrich, & Rothman, 2007). Davis (2001) found that patients age 50 and over were familiar with but had little knowledge about CRC and the digestive system. Specifically, they were unfamiliar with cancer-related terms such as “polyp”, “tumor”, “growth” or “lesion” (T. C. Davis et al., 2001; T. C. Davis et al., 2002).

Patient understanding of screening guidelines have been examined, and tools to increase this have been proposed (Allen et al., 2012; Hanoch, 2004). Allen, et. al. illustrated the high confusion around revised breast cancer screening guidelines in 2009, and called for the development of communication aides and shared decision-making tools for providers to alleviate patient confusion (Allen et al., 2012). However, improving patient understanding of test results has not been the focus of interventions, even though research has tied patient confusion and misunderstanding of results to non-compliance with recommended follow-up care (Jones, Devers, et al., 2010; Jones, Vernon, et al., 2010). Previous research showed that almost 30% of patients who arrive for a colonoscopy procedure are unable to correctly state the reason for the procedure, and many gave incorrect descriptions of the anatomy involved, often stating that the procedure was meant to examine the stomach rather than the colon (King-Marshall et al., 2016). Since misunderstanding and non-adherence is linked with demographic indicators, the need for tools to improve patients’ ability to interpret cancer test results is of vital importance if we aim to eliminate health disparities created by suboptimal education and lower socioeconomic status.

2.3 Fuzzy Trace Theory

Fuzzy Trace Theory (FTT) was developed as a grand theory in psychology in the late 1980s and early 1990s to better understand sophisticated forms of human information

processing, especially the relationship between reasoning and memory (Reyna & Brainerd, 1995). One early tenet was that mature reasoning uses synthesized, “gist” interpretations of materials, which are formed by individual emotion, education, culture, experience, worldview, and level of development, rather than memories of exact content (“verbatim” representation) to make decisions or draw conclusions. This stood in contrast to the belief of the time that memory capacity was positively associated with cognitive reasoning skills. This idea was based on then-recent experiments that showed that adults and children recalled what they learned from an experiment, rather than the actual activity or text that was presented, and the term “Fuzzy Trace” was coined to describe the representation used for reasoning (Bjorklund & Buchanan, 1989). FTT applies to written as well as numerical material; findings suggest that most people, when presented with quantitative information, translate it to a qualitative form, or gist representation. For example, percentages are often translated to words like “most” or “less than half” for ease of interpretation and decision-making.

The implications of FTT for medical information processing and decision making are vast. FTT may explain why communicating precise information about risk may not be effective in preventing certain behaviors, and why some health materials are more effective in communicating a message than others. Implications for informed consent exist. According to FTT, if a patient recalls an informed consent conversation verbatim, i.e. repeats the facts or numbers presented, it is still unlikely that true consent is being given, because the patient has not demonstrated a gist understanding, i.e. bottom-line interpretation of how the procedure is likely to affect him or her (Reyna, 2008).

2.3.1 FTT and Health Literacy

FTT has been used to enhance patient understanding (increasing gist representations) of CRC screening methods. Medical information is inherently presented in a verbatim format, rather than a gist-based one, despite indications that patients prefer the latter. Smith, et. al supplemented the usual information with a gist-based leaflet and tested patient understanding of CRC screening information using simple true/false questions, and revised the questionnaire until patients achieved an acceptable knowledge level (Smith et al., 2013). A follow-up randomized controlled trial to test the effect of the pamphlet on screening intention had limited findings, and the authors concluded that while screening knowledge was increased, a ceiling effect limited the intervention's impact on screening intention. It was noted, however, that individuals with low health literacy were more likely to read the supplementary gist pamphlet than the standard pamphlet provided medical information, indicating that these individuals are searching for more understandable information (Samuel G. Smith et al., 2015).

2.3.2 Numeracy and Fuzzy Trace Theory

Numeracy has been an under-explored construct in health care, although numbers feature prominently in medical information. Reyna et. al. (2008) questioned the unspoken assumption that patients understand and benefit from numerical health information, and went further to question that adequate health literacy implies adequate numeracy. The authors return to Fuzzy Trace Theory to suggest that like verbatim representations, which are literal representations of information but contain little meaning and are therefore not useful in medical decision making, the ability to “know” numbers, that is, be aware of percentages of chance or risk, does not necessarily equate to the ability to use that information to make informed decisions. As this research is still in its infancy, it is

suggested that further research on numeracy include examining the relationship between numeracy and risk perceptions (Reyna et al., 2009).

The authors, in addition to other researchers, have furthermore tied inadequate numeracy to an overestimation of risk and posited that this heightened risk perception leads to avoidance of advantageous health behaviors such as screening, thus impacting health outcomes (Gurmankin, Baron, & Armstrong, 2004; Lipkus & Peters, 2009).

Lipkus et. al. summarize the implications of these findings as follows:

The main challenge for public health and health care is to educate the individual as well as create methods of communicating quantitative information that are understood, accepted and used by the public to encourage adaptive health behaviors and decisions. (Lipkus, 2009)

2.4 Mechanical Turk in Research

Mechanical Turk has risen in popularity among researchers since its inception in 2005 due to the ease and low cost of recruiting large numbers of participants (also called Worker or Turkers), to complete tasks (also called Human Intelligence Tasks, or HITs) released by researchers (also called Requesters). It is estimated that hundreds of academic papers yearly rely on MTurk data (Ipeirotis, 2010a). Several assessments of MTurk data exist and found that relative to other convenience samples, Turkers are generally more diverse than traditional convenience samples, especially college surveys, which are known to be homogenous in terms of age, education, life experience and political engagement (Henry 20018). Furthermore, participants response to experimental tasks in ways similar to other large samples, displaying accuracy within 10% of traditional surveys (Bentley, Daskalova, & White, 2017; Cassese, Huddy, Hartman, Mason, &

Weber, 2013). These findings, combined with the exceptional cost saving offered by the reduction in recruitment time and materials, have propelled MTurk to the forefront of online crowdsourcing.

Amazon restricts exact demographic information about Turkers and is not forthcoming about how Turkers are classified. For example, MTurk conveys a “Master Qualification” on Turkers with many completed tasks and high approval ratings, but the exact mechanism that allow for conveyance of the Master Qualification is unclear. Requesters pay an additional fee (approximately \$.50 per participant) to release their HITs only to those with Master Qualifications. Amazon charges between 20%-40% on top of payments to Turkers as a fee. Additional qualifications, such as specifying the years of birth or marital status of participants, incur additional fees averaging between \$.25 and \$.50 per participant. One can also specify the country of residence of participants, but there is speculation about how this and other demographics are verified and updated. In a 2016 blog post (available here: <https://forums.aws.amazon.com/message.jspa?messageID=717590>), Amazon confirmed that the location of US residents is not updated, and Turkers discuss that they themselves are not able to update their location on MTurk, despite attempts to do so.

Since Amazon does not reveal or accurately track demographic information about Turkers, researchers have taken it upon themselves to collect these data. The most interesting collection of MTurk statistics belongs to Panos Ipeirotis at NYU, who posts MTurk data on his blog Behind Enemy Lines: A Computer Scientist at a Business School. Here he presents data on the number of tasks that are posted and completed each day, as well as the size and variability of the MTurk worker pool. He also launched the

Mechanical Turk Tracker, which provides a daily synthesis of Mechanical Turk activity and demographic make-up (Difallah et al., 2015 {Ipeirotis, 2010 #276; Ipeirotis, 2010a). Ipeirotis describes the MTurk population as consisting of anywhere between 100,000 and 200,000 Turkers, with 50% of the worker population changing every 12 months. Demographically, workers are primarily self-reported residents of the United States (between 50%-80%) and India (between 20%-40%), with United States Turkers being on average younger, more educated and more likely to be female than the general US population. Other researchers have found these same trends and report Turkers as notably younger and more ideologically liberal than the public (Berinsky, Huber, & Lenz, 2012). Workers in the United States were found to use MTurk as a source of supplemental income, while those in India viewed it as a primary means of financial support (Ipeirotis, 2010b).

Critiques abound for the MTurk platform itself. To post a task, Requesters are required to build their own interfaces and workflow systems using HTML, CSS, or JavaScript. This has been cited as a barrier to accessing MTurk and an unnecessary source of potential data error (Difallah et al., 2015). To illustrate this, the code used to post the HIT information for this task is posted in Appendix D. Furthermore, worker exploitation in terms of the dismal pay allotted to some HITs have been reported in the media (Semuels, 2018). A 2016 Pew Research Center survey found that 25 percent of workers who earned money from online job platforms like Mechanical Turk and similar sites did so because no other work was available, leading researchers to question the ethics of using MTurk when workers are limited in their agency (Pittman & Sheehan, 2016).

As a final critique, researchers warn that by filtering all experiments through digital mediums, hands-on experience with (and therefore first-hand knowledge of) the participant is lost, which may turn out to be a detriment to social science (D. Peterson, 2015).

2.5 Conclusion

As stated above, a main concern that arises from the literature is that rates of CRC are rising in adults below the age of recommended screening. The present research examined perceptions of risk and severity of CRC diagnosis, understanding of CRC screening methods, and interpretation of CRC screening results among individuals below the age of screening. Health Literacy and Numeracy were examined to determine if these variables influence perception and should be the focus of intervention. Subsequent recommendations for health interventions to reduce CRC or pre-cancerous conditions in this population are presented. To address previous critiques of Amazon MTurk, workers were paid an average of \$15.00/hour for completing the online questionnaire.

Chapter 3: Generational Differences in Colorectal Cancer Knowledge

Abstract

Introduction Current guidelines recommend that regular screening for colorectal cancer (CRC) begin at age 50; recent research however showed that in the US, rates of CRC are decreasing for those 55 and above but are increasing among adults below the age of 50. The mechanisms behind the rise in CRC rates among younger adults are unclear, and guidelines for screening have not been updated to reflect new findings, despite calls to do so.

Methods 624 individuals under the recommended age of CRC screening participated in an online survey collecting information about perceptions of risk and severity of CRC and knowledge of current screening guidelines and available methods of screening. Participants were divided into generational cohorts and group differences were assessed. Multiple linear regression models examined possible predictors of ratings of risk, severity and knowledge.

Results Findings indicate skewed perceptions of risk and a lack of awareness of CRC screening guidelines and available screening methods among all participants. Those classified as belonging to Generation X reported higher rates of perceived risk of CRC and cancer in general, compared with individuals classified as Millennials. Having an established relationship with a medical provider and high Health Literacy were positively associated with high perceived importance of screening for both CRC and cancer in general.

Conclusion Individuals below the age of 50 may not be aware of the risk of CRC.

Providers should be aware of the increased risk to younger patients and the need to screen symptomatic patients. Providers should furthermore be prepared to discuss accurate risk information and available screening methodologies. Continuous relationships with medical providers may aid in addressing low rates of CRC screening.

3.1 Introduction

Overview Increasing colorectal cancer (CRC) screening has been a focus of public health for decades, hinged upon the fact that with regular screening, CRC can be prevented through the removal of precancerous polyps or treated before spreading (Baron et al., 2008; Holt et al., 2013; Makoul et al., 2009; Sarfaty & Wender, 2007). If detected with Stage I CRC, individuals have a 5-year survival rate of 92%; comparably, Stage II survival rates are between 65% and 87%, depending on the size and location of tumors, and stage III survival rates are between 53% and 90%. If detected at Stage IV, CRC has likely metastasized to other parts of the body, and the 5-year survival rate drops to only 12% (ACS, 2017a). The importance of screening and early detection to reduce CRC morbidity and mortality therefore cannot be overstated.

CRC Risk The number of people receiving CRC screenings has increased, leading to a 3% overall decrease in CRC incidence in the United States between 2001 and 2010 (Edwards, 2010). However, recent findings from a large retrospective cohort study found rates of colon and rectal cancer increasing in adults ages 20-29 (rates of colon cancer increased by 2.4%, and rates of rectal cancer increased by 3.2% in this age group) and 30-39 (1% for colon and 3.2% for rectal cancer) from the mid-1980s through 2013. Further findings included increases in rates of colon cancer (1.3%) and rectal cancer (2.3%) for adults age 40-49, and increased rates of colon cancer (0.5%) and rectal cancer

(2.3%) in adults ages 50-54 over the same period. This is in opposition to trends in older cohorts, where adults age 55 and older experienced a marked decline in rates of CRC in the last three decades (Rebecca L. Siegel et al., 2017). A projection of cancer-incidence rates predicted continued increases in CRC incidence rates among adults under the age of 55 through 2040 (Araghi et al., 2018).

CRC Screening Methods Options for screening for CRC include fecal occult blood test (FOBT), sigmoidoscopy, colonoscopy, virtual colonoscopy, and DNA stool test; these common tests vary by length of time to administer, section of the colon examined, and amount of preparation required (ACS, 2017a). Knowledge of available methods for CRC screening has been shown to be suboptimal, with providers mostly recommending colonoscopy for CRC screening, even though patients have expressed discomfort at the idea of this procedure and a preference for less invasive methods (Schwartz et al., 2013).

CRC Screening Guidelines For the average individual, current guidelines issued by the National Cancer Institute endorse regular screening for CRC beginning at age 50 and continuing until age 75, at intervals determined by family history, comorbidities and previous findings. For individuals with a family history of CRC or irritable bowel syndrome, it is recommended that screening begin earlier, as determined by a gastroenterologist. Based on the more recent findings, however, the American Cancer Society made a qualified recommendation to begin colorectal cancer screening at age 45, for those individuals at average risk, and continue through age 75 (A. Wolf et al., 2018). The recommendations of the United States Preventive Services Task Force (USPSTF) and American Medical Society (AMS) remain to begin CRC screening at age 50. It is unclear how individuals under the current age of screening understand screening

guidelines.

Current Study For this study, we sought to examine the perceived risk, severity, and importance of screening for colorectal cancer among individuals below the current age of screening, as well as their knowledge of CRC screening methods. Using Mechanical Turk (MTurk) we recruited a national sample of older Millennials (25-35 years of age) and younger Generation X-ers (36-45 years of age), as rates of colorectal cancer are increasing in both groups and yet both groups are under the age at which current guidelines recommend regular CRC screenings. The two age ranges allow for a comparison between those who are approaching the age of currently recommended regular CRC screening (36-45 years of age) and those who are farther removed from this responsibility (25-35 years of age). The data for this study was collected in April and early May of 2018, shortly before the America Cancer Society made the recommendation to change the age of screening initiation to 45 years of age, but after the findings of increased rates in younger individuals had received significant media coverage.

3.2 Methods

Study Sample

Amazon Mechanical Turk was used to recruit a national convenience sample of individuals belonging to the two age groups described above. Based on methods employed in previous research by team members (Nguyen et al., 2016), we recruited workers with approval ratings equal to or greater than 98% (meaning previously completed tasks were met with approval) and with more than 5000 Human Intelligence Tasks (HITs) completed, as this ensures high quality work across a high number of completed tasks. All elements of informed consent, including study team contact

information, description of the task, estimated time of completion, and compensation were included in the recruitment statement. Inclusion criteria were acceptance of the task, which implied consent, residing in the United States, and being between the ages of 25 and 45 at the time of the survey. Survey completion took approximately 10 – 15 minutes. Workers received \$3.00 for participating, which equated to between \$12.00 and \$18.00 per hour and was above the average compensation for MTurk Workers (\$6.00 per hour) and above the current national minimum wage of \$7.25 per hour. The University of Maryland, College Park Institutional Review Board reviewed and approved this study.

Measures

Generational Cohort was based on definitions from the Pew Research Center which categorizes Millennials as individuals who, in 2017, were between the ages of 21 and 36, and Generation X as those aged 37-52 in 2017 (Pew Research Center, 2018). The age range for each cohort was slightly adjusted because of MTurk restrictions in specifying the age of participants. We ran three surveys in MTurk, setting the inclusion criteria as those born between 1987-1991, 1982-1986, and 1972-1981, respectively (categories set by Amazon). In order to mirror the ten-year age ranges of previous research (Rebecca L. Siegel et al., 2017) we then grouped individuals by generational cohort, with those aged below 36 categorized as Millennial (0) and those aged 37 and above as Generation X (1). Despite specifying the year of birth, there were seven participants below the age of inclusion: 23 (N=2), 24 (N=2), and 25 (N=3). These individuals were included with the millennial cohort.

Perceived risk and severity of CRC, and *perceived importance of CRC screening*, were based on the following questions, with the answer option consisting of a sliding scale

from 1 (not at all likely) to 100 (very likely):

- How likely do you think it is that **you will develop colon or rectal cancer in your lifetime?**
- If **diagnosed with advanced stage colon or rectal cancer**, how likely do you think it is that **you would die from it?**
- How important is it that **you are screened for colon or rectal cancer in your lifetime?**

The same questions were asked regarding cancer in general (How likely do you think it is that you will develop **any type of cancer in your lifetime**, etc.).

Knowledge of colorectal cancer screening methods was assessed by presenting seven cancer screening tests (Mammography, Colonoscopy, Pap Smear, Stool Blood Test (also known as FOBT), Prostate-Specific Antigen (PSA), Stool DNA test, and Sigmoidoscopy) and asking participants: “Which of these screening tests detect colon or rectal cancer? Check all that apply.” *Knowledge of CRC screening guidelines* was assessed through the following question: “At what age should someone of average risk for colon or rectal cancer begin regular screening?” The answer was open-ended but required a numeric entry and was coded both categorically (with 10-year age intervals) and dichotomously (correct/incorrect, with correct = 50). *Perceived health literacy (HL)* was collected using the four-item measure by Chew (Chew, Bradley, & Boyko, 2004) and coded via previously used categories, with a score between 4 and 15 indicating low health literacy, 16-19 indicating medium (or adequate) health literacy, and a score of 20 indicating high health literacy (King-Marshall et al., 2015).

Previous CRC screening (“Have you ever received a screen for colon or rectal cancer?” (yes/no) and *provider relationship* (“Do you have a provider you see at least once a year” (yes/no) were also included in the analysis.

Previous experience with Cancer was a binary variable and required at least one positive response to the following questions: “Have you even been diagnosed with cancer?”; “Have you ever been diagnosed with a precancerous condition?”; “Has anyone in your family ever been diagnosed with cancer?”; “Has cancer impacted your life in any other way?”

Statistical analysis

All statistical analyses were conducted using SPSS 25. Initial bivariate analysis, using Chi-Square Test or Mann-Whitney U Test (to account for uneven distributions) examined the difference between generational groups by the main variables (gender, race, income, health literacy, previous CRC screening, previous experience with cancer, perceived risk and severity of cancer in general and CRC specifically, and perceived importance of screening, as well as knowledge of CRC screening methods and recommended age of screening initiation). Multivariable linear and logistic regressions examined the predictive power of generational cohort and health literacy on perceived cancer and CRC risk and severity, and knowledge of recommended age of screening initiation. A Poisson regression model examined predictors for the number of correct CRC screens identified by participants.

3.3. Findings

Demographics (Table 3.1)

624 individuals participated in the survey; of these, 44.7% individuals were classified as belonging to Generation X (or Gen-Xers), and 55.3% as Millennials. The sample was split between females (55.6%) and males (44.2%), with one person identifying as other

(genderqueer). 83.5% of participants identified as white or Caucasian, 6.7% as black or African American, and 6.7% as Asian American; 5.6% identified as Hispanic. Most were employed full-time (59.2%) and were not current students (94.4%). 48.4% were married or legally partnered, and 87.1% had some college education or more.

Table 3.1: Participant Demographics (N=624)	Participants (N (%))
Generational Cohort	
Generation X	279 (44.7)
Millennial	345 (55.3)
Identified Gender	
Female	347 (55.6)
Male	276 (44.2)
Other (Genderqueer)	1 (.2)
Race	
Asian/Asian American	42 (6.7)
African American/Black	44 (7.1)
Caucasian/White	521 (83.5)
Other	17 (2.7)
Hispanic – Yes	35 (5.6)
Married or legally partnered- Yes	302 (48.4)
Education	
Elementary School	3 (.5)
HS or GED	78 (12.5)
Some college or college grad	434 (69.6)
Grad school	109 (17.5)
Income	
<20,000	53 (8.5)
20-49,000	229 (36.7)
50-79,000	192 (30.8)
>80,000	150 (24.0)
Employment	
Full-time	466 (59.2)
Part-time	102 (13)

Looking for work	28 (3.6)
Homemaker	58 (7.4)
Current student – no	589 (94.4)
Health Literacy	
Low	124 (19.9)
Medium	394 (63.1)
High	106 (17)
Have you previously been screened for CRC?	
Yes	39 (6.3)
Have you ever been diagnosed with cancer?	
Yes	15 (2.4)
At what age should the average person begin screening for CRC?	
>19	0
20-29	5 (.4)
30-39	65 (10.4)
40-49	292 (46.8)
50-59	247 (39.6)
60+	15 (2.4)
At what age should the average person begin screening for CRC?	
Correct (50 Yo)	225 (36.1)
Which of these tests is a screening method for CRC?	
identified NO correct screen	6 (1)
identified one correct screen	205 (32.9)
identified two correct screens	188 (30.1)
identified three correct screens	176 (28.2)
identified all four correct screens	49 (7.9)

CRC Knowledge

About one third of participants (36.1%) identified the correct currently recommended age of screening initiation (50 years). Other age ranges that were frequently cited as the recommended age of initiation of CRC screenings were 30-39 (10.4%), 40-49 (46.8%),

40 (28%), and 60+ (2.4%). Most individuals were aware (or could deduce) that a colonoscopy is a common method for colorectal cancer screening (96.3%). However, fewer were aware of FOBT testing (59.1%), Stool DNA tests (38%) and Sigmoidoscopy (15.7%) as CRC screening methods. 22.3% of participants believed PSA to be a screen for CRC. 99.8% and 98.7% of participants were aware that mammography and pap smears, respectively, were not tests for CRC. Only 7.9% of participants correctly identified all four CRC screens presented, and 21.5% identified at least one incorrect test for CRC (Mammography, PSA or Pap).

Generational Differences (Tables 3.2 and 3.3)

No significant differences between generational cohorts existed in terms of education, Health Literacy, previous CRC screening, and having a medical provider they see at least once a year. Cohorts did not vary in their perceptions of severity of a CRC diagnosis. Furthermore, no significant differences existed in the perceived importance of CRC screening and the perceived importance of cancer screening in general. Cohorts rated the importance of cancer screening in general at around 72.1/100, and the importance of CRC screening in their lifetime at 71.6/100. Both groups identified on average one correct CRC test out of the four presented, with no significant differences between groups.

Cohorts did differ significantly in terms of gender, race, and previous experience with cancer, with Generation X more likely to be female, identify as white or Caucasian, and have previous experience with cancer. Furthermore, Gen X-ers reported higher rates of perceived risk of CRC (25/100, compared with Millennials at 18/100) and cancer in general (50/100; Millennials = 43/100), and severity of cancer in general (55/100,

Millennials = 53/100). Significant group differences also existed in the knowledge of age of CRC screening initiation, with 47% of Generation X correctly stating age 50 as the age to begin screening, compared with 27.2% of Millennials.

Table 3.2: Group comparisons of continuous variables (Mann-Whitney U Test)

Variable	Range	Median		Mann-Whitney U	Z-score	p
		Millennial (N=345)	Gen X (N=279)			
How likely are you to develop any type of cancer in your lifetime?	1-100	43	50	55670	3.4	<.00
If diagnosed with any type of cancer, how likely are you to die from it?	1-100	53	55	53089	2.2	0.03
How important is it to get screened for any type of cancer in your lifetime?	1-100	75	75	48476	0.2	0.88
How likely are you to develop colon or rectal cancer in your lifetime?	1-100	18	25	53458	2.3	0.02
If diagnosed with colon or rectal cancer, how likely are	1-100	53	55	49,259	0.5	0.61

you to die
from it?

How important is it to get screened for colon or rectal cancer in your lifetime?	1-100	78	79	46824	-0.6	.88
Education	1-17	16	16	48,004	-0.1	0.95

Table 3.3: Group comparisons of categorical variables (Chi-Square Test)

Variable	Millennial	Gen X	χ^2	P
	N(%)	N(%)		
Identified Gender (Female)	172 (49.9)	175 (62.7)	10.3	<.00
Previous CRC Screen (yes)	18 (5.2)	21 (7.5)	1.4	0.25
Previous experience with cancer (yes)	3 (.9)	12 (4.3)	7.7	<.00
Relationship with a Provider (yes)	235 (68.1)	202 (72.4)	1.4	0.25
Race				
African American or Black	29 (8.4)	15 (5.4)	11.8	<.00
Caucasian or White	273 (79.1)	248 (88.9)		
Asian or Asian American	32 (9.3)	10 (3.6)		
Other	11 (3.2)	6 (2.2)		
Health Literacy				
Low	73 (21.2)	51 (18.3)	1.9	0.4
Medium	219 (63.5)	175 (62.7)		
High	53 (15.4)	53 (19.0)		
Which tests identify CRC?				
0 correct	3 (.9)	3 (1.1)	2.4	0.7
1 correct	110 (31.9)	95 (34.1)		
2 correct	109 (31.6)	79 (28.3)		
3 correct	100 (29)	76 (27.2)		

4 correct	23 (6.7)	26 (9.3)		
At what age should the average person begin screenings for CRC?				
Correct (50)	94 (27.2)	131 (47.0)	26	<.00
At what age should the average person begin screenings for CRC?				
>_19	0 (0)	0 (0)	46.5	<.00
20-29	5 (1.4)	0 (0)		
30-39	54 (15.7)	11 (3.9)		
40-49	176 (51.0)	116 (41.6)		
50-59	105 (30.4)	142 (50.9)		
60+	5 (1.4)	10 (1.6)		

Multivariable analysis (Table 3.4)

Stepwise Linear regression models produced significant predictors of perceived risk, severity, and importance of screening, as well as knowledge of CRC screening guidelines and methods. Independent variables for all models were Generational Cohort, Health Literacy, Gender, Race, Income, Relationship with a Provider, and Previous CRC Screen.

Model 1 (“How likely are you to develop any type of cancer in your lifetime”) was significantly associated with Generational Cohort, Race, and Gender, with Gen-Xers, those identifying as white or Caucasian, and females more likely to give higher ratings of perceived risk of cancer in general. Generational Cohort (Gen-X) and Gender (Female) were also associated with the question “If diagnosed with any advance stage cancer, how likely are you to die from it?” (**Model 2**). Health Literacy (High), Race (Asian) and Relationship with Provider (Yes) significantly added to **Model 3** (“How important is it to be screened for any type of cancer in my lifetime?”) and **Model 4** (“How likely are you to develop colon or rectal cancer in your lifetime?”) was associated with Previous CRC

screen and Race, with those who have previously undergone CRC screening and those identifying as non-black scoring their risk of colon or rectal cancer more highly. No significant associations existed for **Model 5**: “If diagnosed with advanced stage colon cancer, how likely are you to die from it?”. **Model 6** (“How important is it to be screened for CRC in my lifetime”) was significant, with Health Literacy (High), Previous CRC Screen (Yes), Relationship with a Provider (Yes), Gender (Female) and Income adding to the model. A logistic regression model (**Model 7**) assessed answers to the question of when one should initiate regular CRC screening. Two of the six predictor variables were statistically significant: Females (compared to males) and those belonging to Generation X (compared with Millennials) were less likely to answer correctly (estimated ORs = .61 and .47, respectively; not displayed in table). Finally, a Poisson regression model was used to examine factors associated with the number of correct responses to the question “Which of these tests identify a screening test for CRC?”. This model (**Model 8**) did not identify any significant association. The corresponding statistics for all significant models (except model 7) can be found in **Table 4**.

Table 3.4: Stepwise Linear Regression Models

Dependent Variable		Significant predictors	B	p	95.0% Confidence Interval	
					Lower Bound	Upper Bound
General Cancer Questions	Model 1: How likely are you to develop any type of cancer in your lifetime?	Gender (Female)	10.41	<0.00	6.39	14.43
		Race (White)	11.53	<0.00	6.15	16.91
		Generational cohort (Gen X)	5.23	0.01	1.12	9.27

	Model 2: If diagnosed with any advance stage cancer type of cancer, how likely are you to die from it?	Gender (Female)	5.01	0.10	1.19	8.84
		Generational Cohort (Gen X)	4.25	0.03	0.43	8.07
	Model 3: How important is it to be screened for any type of cancer in my lifetime?	HL (High)	7.71	<.00	2.44	12.99
		Race (Asian)	9.04	0.03	1.16	16.91
		Relationship with provider (yes)	4.67	0.03	0.35	8.99
CRC Specific Questions	Model 4: How likely are you to develop colon or rectal cancer in your lifetime?	Previous CRC screen (yes)	11.69	<.00	4.53	18.85
		Race (Black)	-7.77	0.03	-14.55	-1.00
	Model 6: How important is it to be screened for CRC in my lifetime?	Previous CRC screen (yes)	13.35	<.00	5.03	21.67
		HL (High)	8.24	<.00	2.86	13.61
		Relationship with provider (yes)	6.13	<.00	1.60	10.67
		Gender (Female)	-5.81	<.00	-9.86	-1.77
	Income	.82	0.02	0.11	1.54	

* All models included generational cohort, race (black, white and Asian), gender, HL (high, medium, low), previous CRC screen, relationship with provider, and income

3.4. Discussion

Generational research has previously been conducted to examine differences and preferences among medical students (Borges, Manuel, Elam, & Jones, 2006, 2010), the health care workforce (Piper, 2012), and patients (DeMaria & Hoffman, 2016; Johanson, 2017), and implications for academic instruction, mentoring, workplace culture, and the general treatment of patients have been discussed. Generational cohort provided a valuable lens through which to examine cancer perceptions and knowledge. Both groups overestimated the risk of CRC, as the lifetime risk for CRC is between 4% and 5% (ACS, 2017b; Campos, 2017), while these cohorts rated the likelihood at 18/100 (Millennial) and 25/100 (Gen X), with Gen-Xers reporting significantly higher CRC risk compared with Millennials. Gen-Xers furthermore reported significantly higher risks of cancer in general (50/100) and greater likelihood of dying of cancer (55/100), compared with Millennials, who have a more realistic view when rating their risk of developing cancer (43/100). However, both groups again severely overestimate the risk and severity, as the actual lifetime risk of developing cancer is around 39.66% for men and 37.65% for women, while the risk of dying from cancer is 22.03% for men and 18.76% for women (ACS, 2017b). (Note that comparing these rates of severity is not completely accurate as our severity question asked about the risk of dying *if* diagnosed with advanced stage cancer, while the ACS statistics report the risk of dying from cancer in one's lifetime).

The importance of cancer screenings in general and CRC screening specifically was rated by both groups between 75/100 – 78/100, indicating that most individuals are aware of the benefits of screening. However, if these rates in the future translate to screening uptake at the age of recommended screening initiation, we will remain at the same suboptimal screening rates for colorectal cancer, as currently only on estimated 60-

76% of age-eligible individuals undergo guideline-concordant CRC screening (CDC, 2019).

Generation X was more likely to be aware of current CRC screening guidelines while Millennials believed CRC screening to begin at a younger age (between 40 and 49). If screening guidelines are changed based on rises in CRC incidence in younger populations, these guidelines will have to be carefully disseminated to this population using targeted interventions. Both groups furthermore showed a lack of awareness of all available CRC screening methods, indicating that more discussion is needed around available screening options, especially as awareness of less invasive methods might lead to an uptake of screening. In addition to CRC screening methods, providers should be prepared to discuss actual cancer and CRC risk and severity rates, especially with patients approaching age 50.

Finally, regression models indicate that targeting subgroups for interventions may be effective. Women, and Gen-Xers reported higher rates of risk and severity, while high Health Literacy and having an established relationship with a provider led to a greater appreciation of the importance of both cancer screening in general and CRC screening specifically. In addition, the finding that individuals who identify as black or African American see themselves at lower risk of developing colon or rectal cancer is concerning, since the inverse is true (Augustus & Ellis, 2018).

Limitations

It is possible, as in any other online survey, that participants misrepresented themselves in their profile to meet inclusion criteria, though this is considered unlikely. Furthermore, participants recruited via MTurk are paid by task completed, and therefore may have

answered survey questions more quickly than general volunteers; however, previous research that used MTurk workers found samples to be as reliable as other internet samples (Buhrmester, Kwang, & Gosling, 2011; Chandler & Shapiro, 2016). Finally, all data were collected via survey at one time point and therefore no conclusions about causality can be drawn. However, we believe these data provide a good starting point for further examination of generational differences in cancer knowledge.

3.5 Conclusion

Incidence and mortality rates of CRC are rising in those below the current recommended age for regular screening, and this trend has been projected to continue for the foreseeable future. While the ACA has called for a lowering of the age of CRC screening initiation to 45 years of age, no formal modifications to the guidelines have been made as of yet. If the recommended age of screening is lowered, careful dissemination is needed to ensure the uptake of screening by those most in need. Physicians must be carefully in tune with symptoms of CRC in this population, which will require attentive and careful communication between patients and physicians so that symptoms are not broadly dismissed. An awareness of the varying perceptions of risk, severity, and importance of screening that may influence use of health care services, as well as the extent of knowledge of screening methods and current guidelines, can guide these conversations.

Chapter 4: “Nothing too outrageous” v. “I am highly concerned”: Variation in descriptions of medical information when presented differently.

Abstract

Background Current guidelines by the American Cancer Society recommend that regular screening for colorectal cancer (CRC) begin at age 50; recent research however shows rates of CRC rising among adults below the age of 50. Increasing rates in this population are occurring despite declining overall rates of CRC. The mechanisms behind this remain unclear, and guidelines for screening have not been updated to reflect new findings.

Current CRC screening reports can be difficult to interpret and consequently lead to non-adherence to treatment recommendation. This study aimed to examine how individuals below the age of 50 interpret a CRC screening report, and if slight modifications to this report can ease the burden of interpretation.

Methods An online survey of individuals between the ages of 24 and 45 was conducted in April and May of 2018. Participants were recruited using Amazon© Mechanical Turk, a crowdsourcing internet marketplace which allows for the quick completion of tasks for compensation. Participants were randomized to receive one of two colonoscopy result reports, the first being a replicate of the report provided by a large, urban medical center in Maryland, and the second a modified report containing a “gist” synthesis of findings. Participants’ open-ended interpretations of these reports were analyzed qualitatively using NVivo 12, and measures of perceived severity of the report, importance of follow-up, and trust in a plan of care were assessed.

Findings Results 2 results showed that individuals who received the modified colonoscopy report correctly rated the report as more serious and rated the importance of follow-up higher than those who received the standard medical report; however, those

who received the standard report were more likely to believe that a plan of care was in place for the fictional patient. Qualitative results showed participants who received the modified report were more likely to understand that results from a biopsy were pending, while those who received the traditional report were more confused about the content.

Significance Current screening reports are difficult to understand and add the burden of translating medical information to the already full plate of the patient. Screening reports that contain a synthesis of findings could help patients understand information more easily and plan next steps accordingly. More research is needed to make recommendations for what this synthesis should contain.

4.1 Introduction

It has long been known that poor literacy skills are predictive of poor health outcomes for patients (Baker, Parker, Williams, Clark, & Nurss, 1997; Weiss, Hart, McGee, & D'Estelle, 1992) and that even patients with adequate literacy can have inadequate Health Literacy (HL) (Graham & Brookey, 2008). Though current estimates for national HL rates are hard to come by, a 2003 national survey estimated that only 12% of United States residents have high HL, with 49% having adequate and 39% low HL ("America's Health Literacy: Why we Need Accessible Health Information. An Issue Brief from the U.S. Department of Health and Human Services.," 2008). HL is increasingly viewed as a characteristic reaching beyond the individual level to families and communities, as well as the organizations that serve them and policies that guide health care implementation and cost (Batterham, Hawkins, Collins, Buchbinder, & Osborne, 2016). HL interventions are therefore focusing less on improving the HL of individuals but instead providing populations with accessible services, health care staff that is trained in patient-centered

care, and health materials that are understandable and useable. Fuzzy Trace Theory (FTT) has been used to guide the development of health materials to optimize understanding (Samuel G. Smith et al., 2015).

Fuzzy Trace Theory (FTT)

FTT was developed as a grand theory in psychology in the late 1980s and early 1990s to better understand sophisticated forms of human information processing, especially the relationship between reasoning and memory (Reyna & Brainerd, 1995). One early tenet was that mature reasoning uses synthesized, “gist” interpretations of materials, which are formed by individual emotion, education, culture, experience, worldview, and level of development, rather than memories of exact content (“verbatim” representation) to make decisions or draw conclusions. That is, material is synthesized to provide an overall estimate of meaning rather than deconstructed around particular arguments and statements. This stood in contrast to the belief of the time that memory capacity was positively associated with cognitive reasoning skills. This idea was based on then-recent experiments that showed that adults and children recalled what they learned from an experiment, rather than the actual activity or text that was presented, and the term “Fuzzy Trace” was coined to describe the representation used for reasoning (Bjorklund & Buchanan, 1989). FTT applies to written as well as numerical material; findings suggest that most people, when presented with quantitative information, translate it to a qualitative form, or gist representation. For example, percentages are often translated to words like “most” or “less than half” for ease of interpretation and decision-making.

The implications of FTT for medical information processing and decision making are vast. FTT may explain why communicating precise information about risk may not be

effective in preventing certain behaviors, and why some health materials are more effective in communicating a message than others. Implications for informed consent also exist; according to FTT, if a patient recalls an informed consent conversation verbatim, i.e. repeats the facts or numbers presented, it does not necessarily imply a deeper understanding (Reyna, 2008).

FTT and Numeracy

Numeracy has been an under-explored construct in health care, although numbers feature prominently in medical information. Reyna et. al. (2008) questioned the unspoken assumption that patients understand and benefit from numerical health information and went further to question that adequate health literacy implies adequate numeracy. The authors return to Fuzzy Trace Theory to suggest that like verbatim representations, which are literal representations of information but contain little meaning and are therefore not useful in medical decision making, the ability to “know” numbers, that is, be aware of percentages of chance or risk, does not necessarily equate to the ability to use that information to make informed decisions. As this research is still in its infancy, it is suggested that further research on numeracy include examining the relationship between numeracy and risk perceptions (Reyna et al., 2009).

Researchers have tied inadequate numeracy to an overestimation of risk and posited that this heightened risk perception leads to avoidance of advantageous health behaviors such as screening, thus impacting health outcomes (Gurmankin et al., 2004; Lipkus & Peters, 2009). Lipkus et. al. summarize the implications of these findings as follows:

The main challenge for public health and health care is to educate the individual as well as create methods of communicating quantitative information that are understood, accepted and used by the public to encourage adaptive health behaviors

and decisions. (Lipkus, 2009)

Current Study

The aim for this mixed-method study was to examine how survey participants described results from a fictional colonoscopy report that presented information in one of two ways: 1. A “standard” report that contains descriptions of findings and recommendations; or 2. A modified, or “gist”, report containing the same findings included in the standard report, but with revised recommendations that summarize findings and next steps. The purpose was to assess variations in how participants summarize the findings. We were specifically interested in the role health literacy and numeracy play in the interpretation of these reports.

4.2 Methods

Pilot Study

During a one-year pilot study, colonoscopy result reports were obtained from one large, urban medical institution. Participants were recruited immediately prior to their colonoscopy procedure (both screening and diagnostic cases were recruited), and demographic and health literacy data collected. Within two months of their procedure, participants were contacted and, if they agreed, interviewed in their home. These interviews lasted between one and two hours, during which all were asked to describe the information presented in the reports, highlight sections that were confusing or helpful, and provide recommendations for improving the report. Participants narrated their thought process while during the activity and interviews were audio-recorded. Among other findings, researchers noted a pattern of participants noting that the medical information presented to them in the reports was appreciated and may be handed to their

primary care physician for reference, but a summary statement of findings and recommendations, written in lay terms, was desirable and would be helpful in determining next steps for the patients themselves (Mueller NM, 2017). Based on these findings, and guided by FTT, the research team constructed a “gist” report, which contained all information from the original medical report but also a revised recommendations section, which synthesized findings. The revised report was read by five lay persons, to determine readability. The pilot study was approved by the University of Maryland, College Park Institutional Review Board, and funded through the University of Maryland MPower Initiative (PI: Curbow). Data were collected August 2015 through September 2016.

Larger Study

As part of a larger online survey (described in detail in Chapter 3), survey participants (N=720) were randomized to one of two fictional colonoscopy reports; 1. The standard version provided to patients after colonoscopy; or 2. The gist report created by the research team. The reports described the same serious findings: likely stage IV colorectal cancer, with two polyps that necessitated removal and one large mass, possibly malignant, that was biopsied. Both the standard medical report and the gist report are available in Appendix C: Questionnaire. Participants were then asked to provide an open-ended description of findings and to indicate their beliefs about the seriousness of findings, importance of follow-up, and existence of a plan-of-care for the fictional person. The University of Maryland IRB approved this study. Data were collected in April and May of 2018.

Measures

Report Descriptives

Participants were asked to read through the colonoscopy reports and answer the following questions: **1. How serious is this report?; 2. How important is it that this patient follow up with a doctor?; and 3. To what extent is there a plan of care in place for this patient?** All answers options ranged from 1 (not at all) to 10 (very much so).

Participants were then asked the following open-ended question: “If this colonoscopy report belonged to a loved one, and he or she asked you what it meant, what would you say?” Participants’ responses to this question were assessed both qualitatively and quantitatively. For quantitative purposes, a binary **verbatim variable** was created to capture those responses that contained verbatim representations of results: This was coded as verbatim (1) or not verbatim (0). To qualify as verbatim, a response had to contain two or more medical words used in the reports, such as the following responses: “The results of the colonoscopy are abnormal and there is a reason to believe that you may have a cancerous mass in your cecum.”; and “You have hemorrhoids and 2 colon polyps, which can develop into colon cancer.” Finally, we asked participants to state whether the recommendations of the report were written in medical language (0) or plain language (1) to determine the success of our randomization.

Health Literacy and Numeracy

Perceived health literacy (HL) was collected using the four-item measure by Chew (Chew et al., 2004) and coded via previously used categories, with a score between 4 and 15 indicating low health literacy, 16-19 indicating medium (or adequate) health literacy, and a score of 20 indicating high health literacy (King-Marshall et al., 2015). *Perceived Numeracy* was assessed using the Subjective Numeracy Scale (Fagerlin et al., 2007;

Zikmund-Fisher, Smith, Ubel, & Fagerlin, 2007), with a summary mean score ranging from 1-6. *Previous CRC screening* was determined by asking “Have you ever received a screen for colon or rectal cancer?”, with a binary scoring (yes/no).

4.3 Analysis

Quantitative analysis

All quantitative analyses were conducted using SPSS v25. Bivariate analyses were conducted to assess differences between the two groups (Gist report and standard report) in terms of age, health literacy, numeracy, income, education and sex. Bivariate analysis was also conducted to compare responses on the three main variables (How serious is this report; How important is it that the patient follow up with a doctor; and To what extent is a plan of care in place for the patient) by report type (standard v. gist). Finally, logistic regression was used to determine the predictive factors of a verbatim response, while controlling for demographic variables.

Qualitative Analysis

Two members of the research team (NM and JY) read through responses to the question “If this colonoscopy report belonged to a loved one, and he or she asked you what it meant, what would you say?” An initial list of codes was created and subsequently collapsed and refined through discussion. Report type was documented as an attribute but arbitrary labels were used to blind coders (report x and report y). Responses were uploaded to NVivo 12 for coding. Questions continued to be resolved through discussions and codes continued to be refined during the coding process. Upon completion, kappa was calculated to assess reliability and was found to be high (>.93).

Coding was then split by report type. Researchers remained blind to report type because of the labeling: However, due to the different content of the reports, report type could be intuited through some responses. As a final step, the research team read through the coding summary and created memos for each report type. The three most salient codes for each report type were summarized and are presented in **Table 4**.

Regression Models

Logistic regression was used to determine the factors that contributed to a verbatim response. Predictor variables were report type received, health literacy, numeracy, and previous experience with cancer. We controlled for age, self-identified gender, and income.

4.4 Results

Participant demographics are displayed in **Table 4.1** and discussed in more detail in Chapter 3.

Table 4.1: Participant Demographics	Participants (N = 720)
Identified Gender (%)	
Female	369 (51.2)
Male	350 (48.7)
Other (genderqueer)	1 (.1)
Age (mean, SD)	35.9 (5.6)
Race	
American Indian/Alaskan Native	9 (1.3)
Asian/Asian American	97 (13.5)
African American/Black	47 (6.5)

Caucasian/White	546 (75.8)
Other	21 (2.9)
Hispanic – Yes	47 (6.5)
Married or legally partnered- Yes	353 (49)
Education	
Elementary School	5 (.7)
Some HS	3 (.4)
HS Graduate or GED	78 (10.8)
1-3 years of college or Associates Degree	218 (30.3)
4 years of College or Bachelor's Degree	277 (38.5)
Graduate School	139 (19.3)
Income	
<20,000	100 (13.9)
20-49,000	251 (34.9)
50-79,000	209 (29)
>80,000	160 (22.2)
Employment	
Full-time	462 (64.2)
Part-time	100 (13.9)
Looking for work	28 (3.9)
Homemaker	58 (8.1)
Other	72 (9.9)
Current student – no	664 (92.2)
Health Literacy	
Low	185(25.7)
Medium	422 (58.6)
High	113 (15.7)

Bivariate Results

Group comparisons (t-test and Chi-square) were run ensure that randomization was successful. Individuals who were randomized to receive the gist report and those who received the medical report were similar in terms of health literacy, numeracy, education, gender and age. A significant difference existed in income, with those receiving the standard report reporting a slightly higher income than those who received the gist report ($t=2.06$, $CI=.1,1$, $p<.01$).

Table 4.2 displays the results of bivariate analysis examining differences in perceptions of the report based on which report version was read. The question “How would you describe the wording of these impressions” was included as an additional check, to ensure that randomization occurred correctly. Chi-square results indicate that it did, with just under 80% of those who received the Gist report describing it as written in a way that allowed most people to understand it, and just under 90% of those who received the medical report indicating that it was written in medical language, which can be difficult to understand for most people ($\chi^2=334.3$, $p<.001$). When asked about the report, participants who read the gist report interpreted it as more serious (Mean=9.2, compared with Standard Report Mean=8.0, $p <.001$), and the importance of follow-up higher (Mean=9.7, compared with Standard Report Mean=9.6, $p <.001$), than those who received the standard report. Those who received the standard report were more likely to think that a plan of care existed for the recipient of the report compared with those who read the gist report (Mean = 7.5 and 7.1, respectively; $p<.001$).

Table 4.2: Bivariate Analysis of Report Impressions by Report Type

	Gist Report (375)	Medical Report (345)	
	N (%)		χ^2 (p)
How would you describe the wording of these impressions?			
It was written in plain language (language that most people can understand) (1)	305 (80.1%)	40 (11.6%)	334.9 (,001)
It was written in medical language (language that a doctor may use, but that can be difficult to understand for most people) (2)	76 (19.9%)	299 (88.2%)	
	Mean (sd)		t (CI)
How serious is this report?	9.2 (1.2)	8.0 (1.8)	-10.6 (-1.3,-.9)*
How important is it that this patient follow up with a doctor?	9.7 (.8)	9.6 (1.1)	-4.1 (-.3,-.1)*
To what extent is there a plan of care in place for the patient?	7.1 (2.3)	7.5 (1.9)	2.8 (.1,.8)*

*Significant at p<.001

Qualitative Results

Table 4.3 shows prominent responses by report type to the question: “If this colonoscopy report belonged to a loved one, and he or she asked you what it meant, what would you say?” For each report type, the three most salient response categories are displayed.

Responses from those who received the standard report were characterized as follows: 1. Participants described the need for follow-up or more information 2. Findings were described using medical terminology; 3. Participants expressed uncertainty or gave vague responses. Responses to the gist report were characterized by the following: 1. The need to wait for results of the biopsy and then follow up with a doctor; 2. The need to wait for

biopsy results (without mentioning further consultation with a provider); and 3. References to the discussion of diet within the gist report. Both groups displayed misunderstanding of certain words (“It looks like the abnormalities are probably malignant, so I wouldn't worry.”; “I would tell them that the report was negative and there is a serious risk of cancer”).

Verbatim Variable

Participants who received the standard medical report were significantly more likely to explain results using a verbatim response; 81 (23.3%) of those who received the medical report explained it using terminology taken directly from the report, compared with 49 (12.9%) of those who received the gist report ($\chi^2 = 13.23, p < .001$). Two logistic regression models were used to further explore this variable; the first featured HL and controlled for age, race, gender, income, and previous experience with cancer. Neither numeracy nor HL predicted a verbatim response; however, allowing borderline significance, individuals with previous experience with cancer were less likely to give a verbatim response than those who reported having no previous experience with cancer (HL Model: OR = .636, $p = .055$; Numeracy Model: OR = .630, $p = .05$). These results are not displayed in a table.

Table 4.3: Qualitative Responses to "If this colonoscopy report belonged to a loved one, and he or she asked you what it meant, what would you say?"

Standard (Medical) Report	
Category	Response
Follow-up with Doctor	I can't understand the terminology. There are a number of questions that I would ask your doctor in order to make the situation clear to us.
	I'd say go get it looked at
	I would try to help them as best as I could, but if there was anything I couldn't answer, I'd tell them to call their doctor to request clarification.
	I would say that they should talk to their doctor
Use of medical terminology	The polyps that were biopsied may be malignant or cancerous. The tissue is being sent for testing and we need to wait for the final results.
	The doctors have found one large mass in the cecum, which they have already taken the biopsies, we need to wait for the result.
	there are some Internal and external hemorrhoids and colorectal surgery to be done and need to check CEA today
	Cecal mass, likely malignant. Biopsied.
Uncertain or vague	It looks like the abnormalities are probably malignant, so I wouldn't worry. You might want to ask your doctor though how risky things are.
	I would say that there were some issues but I don't think it's anything too serious.
	I'm glad it wasn't worse.
	I would say it looks like it serious but I am not totally sure due to all the medical terms and I would use the internet to find out more information on the report terms.
	When performed by specially trained professionals, colonoscopies are extremely safe
Gist Report	

Category	Response
Wait for results and follow-up	This report is very serious and they think you have colorectal cancer. You need to follow up with the surgeon they set you up with and you will be getting blood tests in the mail.
	You have a tumor and you need to see a surgeon also they took a biopsy and will let you know the results. It's very important you follow up.
	You have a mass that is possibly cancer. I know that is is scary to hear that but the doctors have taken a biopsy so we will know for sure whether it is cancerous soon. In the mean time we need to set up an appointment to see a surgeon and get his opinion. You also had a few polyps in your colon that were removed today and there were hemorrhoids as well as infection so it is important that you eat a healthy diet high in fiber to help with the infection. I will be here for you as much as I can and if you feel like you want a second opinion I will help you get that as well.
Wait for results	I would go over it with them in detail, and advise that while it may not look promising, we should wait for the biopsy to come back to see if there are more concerns regarding the mass.
	There is a lot to be concerned about, but let's wait for the results and then plan our attack
	i would say that it's being tested to see if it's serious and be patient
	The doctors think it might be cancer. They're going to send the stuff to a lab to get it checked out, and then get back to you. For now just keep doing what you're doing, and get some fluids and stuff into you. They'll let you know.
	There's a possibility of cancer. Let the doctor perform follow-up tests. You'll know more after.
Diet	They are sending a biopsy to test for cancer, you have hemorrhoids and should eat a more fibrous diet and drink plenty of fluids to reduce the effects of your hemorrhoids.
	It's normal report but you have to follow proper diet
	They said they found something that might be cancer, but they have to test and make sure. They said to eat more fiber.
	I will suggest him to consult a colorectal surgeon and advise him to taken fiber and protein

rich foods.

Start eating more fiber and drinking more water, and we'll deal with whatever else is ahead.

4.5 Discussion and Conclusion

Discussion

Findings indicate that even minor changes to medical texts can result in significant differences in interpretation. Individuals receiving the gist report were better able to register the seriousness of the findings and the importance of follow-up care. However, those individuals were also less likely to feel that a plan of care was in place for the hypothetical patient, perhaps due to the understanding that pathology results were still pending and a plan would be decided on after the exact diagnosis was known.

Both qualitative and quantitative results indicate that those receiving the standard report used more language directly taken from the report in describing the findings. FTT would suggest that this is an indication that the standard report was less likely to be understood by participants, though this was not directly shown in this study. Further research should be conducted to examine the relationship of verbatim responses to patient understanding, especially in terms of informed consent.

Qualitative results further indicated that those who read the standard report felt the need for immediate follow-up with a provider, possibly to have the report explained to them, while the participants who read the gist report stated they would wait for the pathology results and then follow-up with a provider. While the standard report caused more confusion and uncertain responses, both groups misused terms such as malignant, which seemed to be confused with benign, and positive/negative findings, which were used in the more colloquial sense (positive=good, negative=bad). Finally, the inclusion of more specific information on beneficial changes to diet in the Gist report may have been

misguided, as participants tended to latch on to this piece of information, possibly because discussions of diet are familiar and relatable, and provide something tangible to focus on. This information may have overshadowed the more serious findings and the exact content of the Gist synthesis should be further evaluated.

Limitations

Our sample consisted of individuals below the current recommended age of colorectal cancer screening. Health Literacy and Numeracy may be more relevant factors in samples with a wider age distribution. All data were collected via survey at one time point and therefore no conclusions about causality can be drawn. However, we believe these data add to our understanding of how patients interpret medical information.

Conclusion

Medical results should be constructed with the patient in mind. Results from this study can assist in designing practical screening reports. While patients appreciate all medical information provided, a synthesis is helpful to guide next steps. These statements should focus on the most relevant aspects of the findings, saving recommendations for lifestyle changes, if applicable, for discussions with providers. They should be stated in simple, direct language in which patients can see a clear chain of necessary steps. Appropriate services should be available to address patient concerns or anxiety,

Chapter 5: Awareness of Colorectal Cancer Trends Among Individuals Below the Age of 50

Abstract

Background Current guidelines by the American Cancer Society recommend that regular screening for colorectal cancer (CRC) begin at age 50; recent research however shows rates of CRC rising among adults below the age of 50. Increasing rates in this population are occurring despite declining overall rates of CRC. The mechanisms behind this remain unclear, and guidelines for screening have not been updated to reflect new findings.

Younger individuals may not be aware of their CRC risk, and providers may be unaware of the need to screen their younger patients.

Methods An online survey of individuals between the ages of 24 and 45 was conducted in April and May of 2018. Participants were recruited using Amazon© Mechanical Turk, a crowdsourcing internet marketplace which allows for the quick completion of tasks for compensation. We randomized participants (N=720) to receive one of two statements describing trends in the rates of colon cancer, one true and one false, and examined participants' ability to discern true from false information and certainty in the correctness of their response.

Findings Results showed a lack of foundational knowledge among participants to differentiate between correct and incorrect statements regarding colon cancer trends. Interestingly, participants seemed to default to accepting the validity of the statement. Those who believed the statement they read to be true were more confident in their response than those who believed the statement to be false; women were overall less confident in their responses than men.

Significance Individuals below the age of 50 seem unaware of current trends of CRC in

their cohort. Providers should intervene accordingly and provide accurate information on trends and available screening options. Providers should furthermore take note of a bias towards believing credible-sounding information, discuss with patients which medical information they read online, and remind individuals, especially men, to take a more critical stance.

5.1 Introduction

Overview

Increases in colorectal cancer (CRC) incidence and mortality among individuals below the current recommended age of screening initiation have been noted both in the US and developed countries in general (Campos, 2017; R. L. Siegel et al., 2017). A recent projection predicted continued increases in CRC incidence rates among adults under the age of 55 through at least 2040 (Araghi et al., 2018). When CRC is detected individuals below the age of 50, it is usually found at an advanced stage and mortality rates are higher (Campos, 2017). It is therefore critical that we begin discussing CRC in younger populations and the actions we can take to optimally prevent this pathology. To our knowledge, there has been no examination of what individuals below the age of 50 know about current CRC trends.

In the United States, individuals have reported high levels of trust in information received directly from providers; 69.5% of respondents to the Health Information National Trends Survey (HINTS) trusted health information from a doctor a lot, while 1.4% reported trusting it not at all. Trust in medical information found online was fairly low, with 13.7% of respondents reporting they would trust online information a lot, and 8.7% stating they would trust it not at all (Hesse & Moser, 2018). Despite their mistrust,

individuals in the US (and around the world) are using the computer more and more to search for medical information, with women more likely to search online for health information than men (Percheski & Hargittai, 2011). One in three adults is said to use the internet to diagnose or learn about health issues (Fox & Duggan, 2012), and trust in content increases when it is easy to use and the authority of the author is recognized (Sbaffi & Rowley, 2017). Furthermore, despite their trust in provider information, patients tend not to adhere to recommendations; for example, an estimated 50% of medications are not taken correctly or at all (Brown & Bussell, 2011). This is likely because trust does not equate to understanding, and despite healthcare professionals' assumptions that medical instructions and information are easy to understand, patients often struggle to do so (Cornett, 2009).

Current Study

This study randomized survey participants to receive one of two statements about rates of colon cancer in the United States, one true and one false. Our goal was to ascertain if younger adults were aware that CRC rates were rising in the under 50 population, while declining for older Americans. We hypothesized that if aware, individuals would recognize the false information as indeed false.

5.2 Methods

Sample

In April and May 2018, an online survey was conducted using Amazon Mechanical Turk (MTurk). Participant demographics are presented in **Table 8**, and the details of this survey have been described previously in Chapter 3. The University of Maryland,

College Park Institutional Review Board approved this study.

Measures

For this study arm, participants were randomized to one of the two below statements about colorectal cancer rates in the United States:

1. **From the mid-1980s through 2013, colon cancer rates:**
 - **declined** in adults age 55 years and older
 - **increased** by 2.4% per year in adults 20 to 29 years
 - **increased** by 1% per year in adults age 30 to 39 yearsor
2. **From the mid-1980s through 2013, colon cancer rates:**
 - **increased** in adults age 55 years and older
 - **declined** by 2.4% per year in adults 20 to 29 years
 - **declined** by 1% per year in adults age 30 to 39 years

Statement 1 is correct (Sigel 2017), while statement 2 is incorrect. Following presentation of the statement, individuals were asked the following questions:

- **What do the data say is happening to colon cancer in the US?** This questions allowed for an open-ended response.
- **Do you think this statement about colon cancer is false (0) or true (1)?**
- **On a scale of 0 (not at all sure) to 10 (completely sure) how sure are you that your answer to the last question is correct?**

(To note, at the conclusion of the survey, participants were automatically directed to an informational page containing the correct statement about CRC trends.)

In addition to the demographic variables collected in **Table 9**, **perceived health literacy (HL)** was collected using the four-item measure by Chew (Chew et al., 2004) and coded via previously used categories, with a score between 4 and 15 indicating low health literacy, 16-19 indicating medium (or adequate) health literacy, and a score of 20 indicating high health literacy (King-Marshall et al., 2015). HL was also used as a continuous variable in the regression analysis, with a range of 4 (low health literacy) to 20 (high health literacy).

Analysis

Quantitative data were analyzed using SPSS 25. Sample descriptives are presented in Table 1 and discussed in more detail elsewhere. The two groups (correct statement and incorrect statement) were compared by demographic factors to ensure randomization was successful. Chi-square and Mann-Whiney U Test were used to assess differences in education, income, gender, race, age, marital status, previous experience with cancer, previous colorectal cancer screen, health literacy and numeracy. Results are presented in Table 2. Open-ended responses were analyzed by group to assess participants' understanding of statements. Results and examples are summarized in the findings section. Finally, a multivariable linear regression assessed the factors predictive of high confidence in individuals' assessments of statement correctness.

5.3 Findings

A description of the study sample can be found in **Table 5.1**. Bivariate analysis (**Table 5.2**) revealed no significant differences between participants who received the correct statement and those who received the incorrect statement, indicating successful randomization. Qualitative analysis of responses indicated that individuals were able to understand the statement provided. Representative examples of responses to the false statement are as follows: "Increasing in older adults, decreasing in younger adults", and "It is more likely in older people". Participants who received the true statement described it with the following terminology: "Declining in over 55s but increasing in 20-39 year olds [sic]" and "Chances decrease as you get older." Few individuals gave ambiguous responses such as "After 1975 anyone can get cancer", and "Increasing", and even less responded with "I don't know."

Table 5.1: Participant Demographics	Participants (N = 720)
Identified Gender (%)	
Female	369 (51.2)
Male	350 (48.7)
Other (genderqueer)	1 (.1)
Age (mean, SD)	35.9 (5.6)
Race	
American Indian/Alaskan Native	9 (1.3)
Asian/Asian American	97 (13.5)
African American/Black	47 (6.5)
Caucasian/White	546 (75.8)
Other	21 (2.9)
Hispanic – Yes	47 (6.5)
Married or legally partnered- Yes	353 (49)
Education	
Elementary School	5 (.7)
Some HS	3 (.4)
HS Graduate or GED	78 (10.8)
1-3 years of college or Associates Degree	218 (30.3)
4 years of College or Bachelor’s Degree	277 (38.5)
Graduate School	139 (19.3)
Income	
<20,000	100 (13.9)
20-49,000	251 (34.9)
50-79,000	209 (29)
>80,000	160 (22.2)
Employment	
Full-time	462 (64.2)
Part-time	100 (13.9)
Looking for work	28 (3.9)

Homemaker	58 (8.1)
Other	72 (9.9)
Current student – no	664 (92.2)
Health Literacy	
Low	185(25.7)
Medium	422 (58.6)
High	113 (15.7)

Table 5.2: Bivariate Comparison of Groups (Chi-square for categorical and Mann-Whitney U Test for continuous)

		Statement Received N(%)		X2	p
		TRUE	FALSE		
Health Literacy	Low	87(23.8)	98 (27.7)	4.4	0.11
	Medium	212 (57.9)	210 (59.3)		
	High	67 (18.3)	46 (13)		
Race	Black	27 (7.4)	20(5.6)	2.5	0.5
	White	280 (76.5)	266 (75.1)		
	Asian	47 (12.8)	50 (14.1)		
Gender	Other	12 (3.3)	18 (5.1)	0.05	0.9
	male or other	177 (48.4)	174 (49.2)		
	female	189 (51.6)	180 (50.8)		

		Statement Received N(Median)		U	z	p
		TRUE	FALSE			
Age		366 (35)	354(35)	64,116	-0.1	0.8
Income		366(6)	354(6)	63,038	-0.6	0.5

ANOVA results (**Table 5.3**) showed that individuals who correctly identified the statement as true (N=288) and those who incorrectly identified the statement as true

(N=307) were more confident in their response than those who identified their statement as false, correctly or incorrectly. A two-way ANOVA (**Table 5.4**) shows a statistically significant interaction between Statement Received and Correct Answer Identified for Confidence scores ($F=29.54, p<.001$). Plots for this interaction are available in Appendix A: Methods, Figure A4. Multiple linear regression examined the predictive power of Health Literacy, Age, Gender and Income on confidence in the correctness of response. Only gender was significant, with females reporting lower scores of confidence in their response than males ($B= -.094; CI=-.752,-.086; p=.014$). Results are presented in **Table 5.5**.

Table 5.3: One-way ANOVA of Statement Received and Response Type.
Dependent Variable = Confidence in Response

Statement received	Response to statement	N(%)	Mean (SD)	95% Confidence Interval for Mean	
				Lower Bound	Upper Bound
Statement 1 (True)	Incorrectly identified as false	86 (11.6)	4.7 (2.4)	4.23	5.26
	Correctly identified as true	280 (38.9)	6.1 (2.2)	5.88	6.39
Statement 2 (False)	Incorrectly identified as true	299 (41.5)	6.2 (2.1)	5.98	6.44
	Correctly identified as false	55 (7.6)	5.4 (2.6)	4.74	6.12

Model significant at $F=12.6, p<.001$

Table 5.4: Two-Way ANOVA of Statement Received and Response Type.
Dependent Variable = Confidence in Response

	Sum of Squares	Degree of Freedom	F	p-value
Correct Statement Identified (yes/no)	6.74	1	1.4	.24
Statement Received (true/false)	14.96	1	3.12	.08
Correct Statement Identification*Statement Received	142.22	1	29.54	<.001

Table 5.5: Multiple Linear Regression Assessing Predictors of Confidence in Response

	95.0% Confidence Interval			p
	B	Lower Bound	Upper Bound	
Health Literacy	-0.03	-0.1	.04	.37
Age	-0.02	0.05	.13	.27
Gender (Female)	-0.44	-0.77	-0.10	.01
Income	-0.01	0.07	0.05	.71

5.5 Discussion

Qualitative review of participant responses indicate that the medical information presented was understood. However, there was a lack of knowledge to differentiate between correct and incorrect statements. Interestingly, participants seemed to default to accepting the validity of the statement, with 579 out of 720 participants classifying the statement as true, regardless of which statement they received. Two-way ANOVA suggests that participants' confidence in interpretation of the statement depended on their response: those who received the true statement and correctly identified it as true were more confident in their assessment than those who received the false statement and

correctly identified it as false. This indicates that individuals are hesitant to disbelieve information when unsure, and has important implication for discussion of online medical information. Providers should be aware of this bias among their patients and discuss strategies for assessing the validity of medical information

Strengths and Limitations

It is possible, as in any other online survey, that participants misrepresented themselves in their profile to meet inclusion criteria, though this is considered unlikely. Furthermore, participants recruited via MTurk are paid by task completed, and therefore may have answered survey questions more quickly than general volunteers; however, previous research that used MTurk workers found samples to be as reliable as other internet samples (Chandler & Shapiro, 2016). Finally, all data were collected via survey at one time point and therefore no conclusions about causality can be drawn. However, we believe these data provide a good starting point for further examination of generational differences in cancer care.

Conclusion

Individuals below the current age of recommended regular CRC screening lack foundational knowledge about CRC trends. This likely indicates that they are unaware of their own risk status and may not recognize symptoms of CRC, should they arise. Providers should take note of this lack of knowledge and intervene. Providers should furthermore be aware of a bias towards believing credible-sounding online information, especially among men. Taking the time to address this during medical visits could lead to a more critical approach among patients when searching for online medical information.

Chapter 6: Summary

6.1 Overview of Findings and Implications

This dissertation was prompted by two factors. The first of these was previous research by the University of Maryland colorectal cancer study team, led by Dr. Barbara Curbow, which investigated how patients, when presented with colonoscopy reports, interpret and use this information. For this research, which served as a pilot study for this survey, we obtain a standard colonoscopy report from a nearby urban medical system and made alterations, based on Health Literacy literature, so that we were left with three different reports. The first was the standard report, which contained a text description of findings and recommendations, as well as small pictures of the colon taken during the procedure. For the second report, we removed the pictures and left only the text. Finally, for the third report, we removed the pictures but added metaphorical descriptions of findings. For example, the text would read as follows: “A 5mm polyps (about the size of a blueberry) was found.” Metaphors have previously been found helpful in describing medical concepts to patients with low HL (Gallagher, McAuley, & Moseley, 2013; Krieger, Parrott, & Nussbaum, 2011). These reports were presented to patients who had recently undergone a colonoscopy at the same medical system and had been recruited to participate just prior to their procedure. Participants were asked to read through all three reports and narrate their thought process as they underlined passages they thought were helpful, confusing, or concerning. Interestingly, the results from this pilot study showed us that rather than finding them helpful, participants across HL levels were confused by the metaphors and mostly ignored the pictures. Participants repeatedly stated that they appreciate the thorough findings provided, even if they were unable to understand some

or most of it, as they would take it to their provider for discussion. However, in addition they would appreciate a synthesis statement at the end of the report that would present important findings and recommended next steps in lay terms. Based on this feedback, and guided by Fuzzy Trace Theory, I designed the gist report used in this survey.

At the same time, new findings reported that rates of colon and rectal cancer were increasing in individuals below the current recommended age of screening (R. L. Siegel et al., 2017). It has been known that when CRC is detected in younger people, it is usually at a more advanced stage than when it is detected in those above the age of 50, compounding the importance of this finding (Campos, 2017). I therefore designed a survey for participants under the age of current recommended screening to assess the following: 1. What does this population perceive and know about colon and rectal cancer? and 2. When presented with a CRC screening report, what information does this population take away from it, and which factors influence this? The goal was to create provider and systems-level recommendations for addressing shortcomings in CRC knowledge and producing medical information that is understandable and usable. The below aims and hypotheses guided the inquiry

6.1.1 Aim 1

Aim: Compare differences in perceived risk to CRC and severity of CRC diagnosis between generational cohorts.

H1: GenXers report higher levels of perceived risk to CRC, compared with Millennials.

H2: Millennials are more likely to think a CRC diagnosis will result in death, compared with GenXers.

Our hypotheses were based on the fact that even though rates of colorectal cancer are increasing in adults below the age of 54 (Rebecca L. Siegel et al., 2017), national

guidelines still set the average age of CRC screening commencement at 50 (ACS, 2017a). These guidelines may lead to the perception that CRC is exclusively a disease related to aging, and younger individuals may not be aware of the risk of CRC (Rabin, 2017). At the same time, lack of knowledge about a condition may lead to the overestimation of severity (Reyna et al., 2009). We therefore posited that Millennials are less aware of factors surrounding CRC and therefore are less aware of their risk to CRC, while at the same time they overestimate the severity of a diagnosis. These hypotheses were tested using Question 33 (perceived risk to CRC) and Question 34 (perceived severity of CRC diagnosis) of the questionnaire.

These hypotheses were not supported by the research findings, as the data show no group differences in perceptions of CRC risk and severity. Additionally, both groups overestimated the risk of CRC, indicating an across-the-board lack of knowledge about the condition and preventive measures.

Gen-Xers also reported significantly higher rates of risk and severity to cancer in general. This may indicate that while CRC is not a high concern of those below the current age of screening, a general sense of cancer risk and severity increases as one ages. This information can be useful to providers in guiding discussion about risk and severity of specific types of cancer, especially when carefully considered in terms of family history and lifestyle.

6.1.2 Aim 2

Aim: Assess knowledge of CRC screening methods and guidelines between age groups.

H3: GenXers score higher on measures of knowledge of CRC screening, compared with Millennials

This hypothesis was partially supported by the data. Significant group differences existed in the knowledge of age of CRC screening initiation, with 46% of Generation X correctly stating age 50 as the age to begin screening, compared with 27% of Millennials, suggesting that as one approaches the age of recommended screening initiation, knowledge of the guidelines increases. Besides belonging to Generation X, being female was a predictor of knowledge of current screening guidelines.

Generation X and Millennials identified on average one out of four CRC screening methods, indicating that a lack of knowledge of available methods spans generational cohorts. This information supports revised guidelines with a younger age of screening initiation, as this may increase knowledge of guidelines in younger cohorts. Providers should also take note that men may need more targeted information about guidelines.

6.1.3 Aim 3

Aim: Assess participants' relationship with a provider and the impact the relationship with a provider has on CRC screening knowledge and perceptions of risk

H4: GenXers more often report having a provider whom they see regularly than Millennials.

H5: Participants with an established relationship with a provider display more CRC knowledge compared with participants without an established relationship.

The above hypotheses were not supported by these data. Surprisingly, high numbers of both Millennials (67.8%) and Gen-Xers (73.1%) reported having a provider they see at least once a year. In a multivariable linear regression model, the relationship with a provider variable predicted higher ratings of the importance of CRC screening, along with being male and higher income. Provider relationship did not predict perceived risk or severity of CRC. The variable itself may not have been specific enough nor captured

the quality of the provider relationship. Future research may begin with a qualitative exploration of a provider relationship and the CRC discussions that take place to better understand the role this relationship takes in CRC prevention.

6.1.4 Aim 4

Aim: Assess whether participants who receive a colonoscopy report formatted to contain Gist information report different perceptions about the report than participants who receive a standard colonoscopy report.

H6: Participants who receive Report 1 (verbatim) provide lower scores of perceived seriousness, compared with participants who receive Report 2.

H7: Participants who receive Report 1 (verbatim) rate the importance of follow-up lower than participants who receive Report 2.

H8: Participants who received Report 2 (gist) are more likely to agree that there is a plan of care in place for the patient, compared with participants who receive report 1.

Exploratory: How would patients describe the reports to their loved ones, and how does this differ by report type?

Fuzzy-Trace Theory (FTT) guided the design of Report 2 (Reyna, 2008, 2012; S. G. Smith et al., 2015). Information presented in medical jargon has been shown to cause confusion and anxiety among patients (Herber et al., 2014; Schnitzler et al., 2017). These hypotheses stated that those who received synthesized findings (the Gist report) would be better equipped to recognize the seriousness of both the report itself and the importance of follow-up. Furthermore, we posited that those who received the Gist report would be more likely to state that they feel a plan of care is in place for the hypothetical patient, compared with those who read the standard report. These hypotheses were tested using Question 23 of the report. Data supported H7 and H7; participants who received the Gist report rated the seriousness of the report and the importance of follow-up more highly than those who received the standard report. H8 was not supported by the data.

Participants who received the standard text report were more likely to feel that there is a

plan of care in place for the hypothetical patient. While the exact nature of this cannot be intuited from these data, we suspect that this is related to the lower perceived seriousness reported by the same group. That is, because these participants did not perceive the report as quite so seriousness as the participants who read the Gist report, they were more likely to state that they were in good hands. Further research should be conducted for the design and optimization of the report and the resulting effects on patients.

Question 25 (If this report belonged to a loved one, and he or she asked you what it meant, what would you say?) was used to test the exploratory aim. Results showed that those who received the Gist report were more likely to take a two-pronged approach to follow-up, that is, wait for pathology results and then follow-up with their doctor to discuss next steps, while those who received the standard report stated that their first move would be to follow-up with their doctor. Those who received the standard report also displayed more confusion about findings and used more verbatim language to describe the findings, with 81 (23.3%) of those who received the standard report explaining results using terminology taken directly from the report, compared with 49 (12.9%) of those who received the gist report. Taken together, these findings suggest that individuals who received the standard report had more difficulty understanding the content and wanted to see a provider for clarification. Future research on the design of medical reports should test whether a better understanding of the seriousness of findings, and an appreciation for the importance of follow-up, translate to an actual increase in follow-up and treatment adherence, when compared with standard of care.

6.1.5 Aim 5

Aim: Randomize participants to receive either a false or true statement describing

current trends of CRC and examine rates of belief and disbelief of the statement, as well as confidence in the accuracy of the assessment.

H9: When asked if a statement about colon cancer trends is true or false, participants with lower HL are more likely to believe in the correctness of their assessment, compared to those with higher HL.

The final aim was explored through a two-way ANOVA and multiple linear regression. ANOVA showed that regardless of which statement was received, participants defaulted to believing in the validity of the statement, with 288 participants correctly identifying the statement as true, and 307 participants incorrectly identifying the statement as true, compared with 56 who correctly identified it as false and 86 who incorrectly identified it as false. A multivariable linear regression explored H9 and results did not support the hypothesis, as health literacy did not predict confidence in a response. Being female was inversely related to confidence in a response. Further research should examine the implications of confidence in one's ability to correctly identify true and false online medical information, paying special attention to gender differences.

6.3 Strengths and Limitations

The general limitations of cross-sectional survey data apply to this study, that is, all data were collected from participants at one period of time. No inferences about causality can therefore be made. In addition, the sample likely suffers from non-response bias, as those individuals who did not participate in the study likely differed from those who did, resulting in a non-representative sample. From previous research, we know that individuals with access to the internet are, on average, more highly educated and have higher incomes than those who are not, though this trend is equalizing with the proliferation of smart phones (Rech Wachelke, Vizeu Camargo, Lincoln Bezerra Lins, & Vieira de Lima Nunes, 2011). Furthermore, our sample consisted of individuals below

the current recommended age of colorectal cancer screening. Health Literacy and Numeracy may be more relevant factors in samples with a wider age distribution. Finally, because of the limited information shared by Amazon, it is unclear how some variables, such as location or age, are reported and if they are updated or not. Participants recruited via MTurk are paid by task completed, and therefore may have answered survey questions more quickly than general volunteers; however, previous research that used MTurk workers found samples to be as reliable as other internet samples. The limitations of using MTurk are discussed in more detail in Appendix A: Methods.

Despite these limitations, cross-sectional data are useful for establishing prevalence of beliefs and knowledge, in this case as related to CRC. Cross-sectional data also ensure that there is no loss to follow-up, as participation is required only once. Because participants were required to answer questions to proceed, and because open-ended questions required responses of a certain type (i.e. the response to “How old were you on your last birthday?” had to be a numeric entry between 1 and 100), missing data and data errors were minimized or eliminated. Finally, this is the first study we know of that examines beliefs and knowledge of CRC specifically in individuals below the current age of recommended screening and tests the influence of health literacy and numeracy.

6.4 Future Research Directions

The research presented here provides many avenues for further research. Firstly, it is clear that a lack of knowledge of CRC guidelines and methods is pervasive, and this lack of knowledge may be translated to overestimates of risk of CRC. Provider discussions should contain realistic explanations of risk and severity, carefully considered in light of family history and current symptomatic status. We agree with previous

research that states the need for more caution when evaluating younger, symptomatic patients and awareness of the consequences of a late diagnosis (Campos, 2017), and add that a greater awareness of available methods of CRC detection may lead to an update in screening rates. There are possibilities for educational interventions to address this, and future research should examine whether tailored provider discussion of risk, severity, and available methods of screening lead to an increase in screening utilization among younger patients. Physicians should be reminded of the importance of taking a family history, as the existence of younger family members with CRC or a first-degree relative with CRC are considered risk factors for CRC, and the patient should consider early screening (Forsberg et al., 2015). We should furthermore explore why, though individuals seem to conceptually understand the importance of cancer and CRC screening, rates among those currently at the age for CRC screening remain suboptimal: for example, is awareness of the importance of screening on the rise, and does this translate to an uptake of screening in practice? Future research should examine factors that promote critical thinking in the wider population. Calls for critical thinking among healthcare professionals proliferate and a universal definition that combines the popular constructs of biomedical, humanist and social-justice oriented critical thinking is sought (Kahlike, 2018). At the same time, it may be worth considering how these critical thinking skills can be passed on or encouraged in the patient population, in tandem with health literacy efforts.

Policy Implications

As CRC rates are expected to continue to rise in this younger population, consideration and planning is needed to ensure that disadvantaged groups benefit from any changes to

screening policies. Incidence rates will need to be monitored closely and examined for racial disparities, as delayed decreases in CRC incidence in US blacks, when compared with US whites, was noted in overall CRC incidence rates (Araghi et al., 2018). Health care providers, health plans, insurers, employers, policy makers, and researchers should focus resources on helping people to address lifestyle issues related to colorectal cancer, beginning at an age much earlier than previously thought. Public health efforts should be closely attuned to new medical findings concerning the etiology of CRC in younger populations, and public health officials should be at the ready to translate these findings into new or adapted strategies to reduce the burden of CRC. Thorough examinations of the cost-effectiveness of CRC screening programs in younger populations is critical to ensure the optimal use of available resources (Subramanian et al., 2016). Economic measures should be devised to standardize the cost of CRC screenings.

Clinical Implications

Based on this research, we support the idea of lowering the recommended age of screening initiation provided that screening options and risk of CRC are clearly presented. Educational intervention for providers may be necessary to ensure that all available screening methods are known and a shared decision between provider and patient can be made about which method constitutes the best fit, taking into account factors such as patient anxiety about invasive procedures, cost or extent of health insurance coverage, and other variables that may bar completion of the screening procedure.

In addition, we advocate for more research on the inclusion of a Gist statement in CRC screening and diagnostic reports. This should explore whether or not a better

understanding of results translates into better follow-up and more decision-making in the cancer care process. Furthermore, it should be examined if tailoring the content of the Gist statement to specific populations, based on patient input, is feasible and effective.

Conclusion

Existing interventions that have increased rates of CRC screening could easily be applied to a younger population. Successful interventions include creating a reminder system for providers to discuss CRC screening with patients and handing out FOBT screening kits as standard of care, for example when receiving an annual flu-shot (Rat et al., 2018). A reminder system and list of questions to screen younger patients for CRC family history and current symptoms could be implemented and FOBT kits could be provided during well-visits. Additionally, public health officials should work closely with the medical community to ensure that superior tests, such as the fecal immunochemical test (FIT), are introduced efficiently into practice.

Appendix A: Methods

Sample Description

Participants consisted of a convenience sample recruited through Amazon's Mechanical Turk (MTurk), an online marketing place that allows researchers to quickly access large numbers of individuals to complete tasks ranging from translation services to survey completion. These tasks are called Human Intelligence Tasks (HITs), because they require humans instead of machines to be completed, and individual "workers" or "Turkers" are compensated per HIT completed. Individuals requesting the work to be done are called "Requesters." Once a task has been submitted by a Requester, it becomes available to workers that meet the inclusion criteria, who can then choose whether or not to complete the task. If the task is completed, the Requester can review the work and decide whether it meets the standards set forth in the request: If it does not, payment can be denied. This has negative consequences for the worker; when Requesters send out tasks, they can specify that only workers with low payment denial rates can complete it (Amazon, 2017).

The use of MTurk is becoming popular among social science researchers because it allows for the recruitment of large sample sizes in a short period of time and with minimal expense. Previous studies have found the MTurk population to produce reliable and valid results that are not significantly different from most other convenience samples, though the MTurk population was found to be more diverse than standard internet samples or American college samples (Buhrmester et al., 2011; Goodman, Cryder, & Cheema, 2013; Nguyen et al., 2016). When 3,006 MTurk participants were compared with those in another large internet sample, it was found that gender splits were

approximately the same in both (MTurk sample 55% female, internet sample 57%). Also, 36% of Turkers were non-white, compared with 23% in the internet sample; furthermore, Turkers were older on average (32.8 years v. 24.3 years) and featured similar numbers of non-Americans (31%). Previous research outlines the steps to take to ensure high-quality responders and maintaining data security when collecting data using MTurk (Mason & Suri, 2012; Nguyen et al., 2016).

Sampling Procedure

Based on previous research, we recruited workers with approval ratings equal to or greater than 98%, and with more than 500 HITs completed, to ensure high quality results and a familiarity with MTurk. Initial inclusion criteria were acceptance of the task, which implies consent, having achieved Master Qualification on MTurk, and being between the ages of 25 and 46 at the time of the survey. Achieving Master Qualification requires that Turkers have an approval rating above 98, and have completed at least 500 HITs. These scores are based on ratings given by previous Requesters, and indicate that Turkers follow instructions and complete tasks, ensuring a high quality of responses. However, after launching the survey and enrolling no more than 239 individuals, we removed the Master Qualification as inclusion criteria. We retained the criteria that approval ratings were equal to or greater than 98%, and Turkers had more than 500 HITs completed.

We aimed to recruit up to 800 individuals total that fit the above described inclusion criteria, with 400 participants between the ages of 25-35 (older millennials) and 400 participants between the ages of 36-46 (younger GenXers). We initially ran two pilot surveys to test the MTurk procedures and accessibility of the questionnaire, with 10 participants each. Subsequently, coding was entered into the larger survey that barred

those who completed the pilot from participating in the larger study. In April 2018, the larger survey was launched in three arms, with each arm specifying a year-of-birth range pre-set by Amazon (Amazon categories: Born 1972 to 1981 (Age 35-45); Born 1982 to 1986 (Age 30-35); Born 1987 to 1991 (Age 25-30)). 239 Turkers accepted the task, after which enrollment stalled. The Master Qualification requirement was removed, and the surveys were re-launched, again specifying that those who previously completed the survey were not eligible to participate again. The subsequent Workers who accepted the task were not necessarily non-Masters, but this variable was no longer available to us once the requirement was removed. In total, 784 Workers accepted the task.

Missing Data

Missing data were minimal, as respondents were required to answer a question to proceed in the survey and required to complete the survey to receive a payment code. 784 Turkers accepted the HIT, 12 of these answered no questions, and a further 45 dropped off around the time of the colonoscopy report reading. This could have been because the report required time to read, the terminology was intimidating, individuals were interrupted, the report was being viewed on a mobile screen and was difficult to read, or for multiple other reasons. Because no demographic data had been collected on these individuals at this point, they are excluded from the final analysis, resulting in an N=727.

Possible Bots

During the summer of 2018, MTurk Requesters noted a drop in data quality and an increase in clusters of geolocation indicators. This raised flags that individuals were running programs (or “Bots”) to complete HITs. While Amazon’s policy allows Workers to run programs to more efficiently help select and preview HITs, it does not allow the

running of programs to complete them. While there is no way to guard against this, a way to assess for Bot data is to carefully examine open-ended responses for nonsense answers such as “nice” or “good” (Dreyfuss, 2018). Using this criterion, we examined open ended responses and flagged seven participants as possible Bots. Bot answers included the following: “hfffffffffffffffff”; “Nothing”; test test”, “none” and “nice work.” Six out of the seven Bots were located outside of the United States. Three Bots identified as female, all seven reported low health literacy, six identified as Millennials, and four identified as Asian. These participants were removed from all analysis, further reducing the general sample size (N=720).

Comparison of Master Qualification vs. no Master Qualification

As stated, above, no data were available as to whether or not the second batch of survey participants had Master Qualifications or not. However, we wanted to compare participants in the first survey batch to those in the second. Chi-square tests showed that there were no significant differences in gender, race, perceived health literacy, numeracy, income or location (US or non-US) between these groups. In addition, there was no significant difference in belonging to a generational cohort (Millennial or Gen-X) between masters and non-masters.

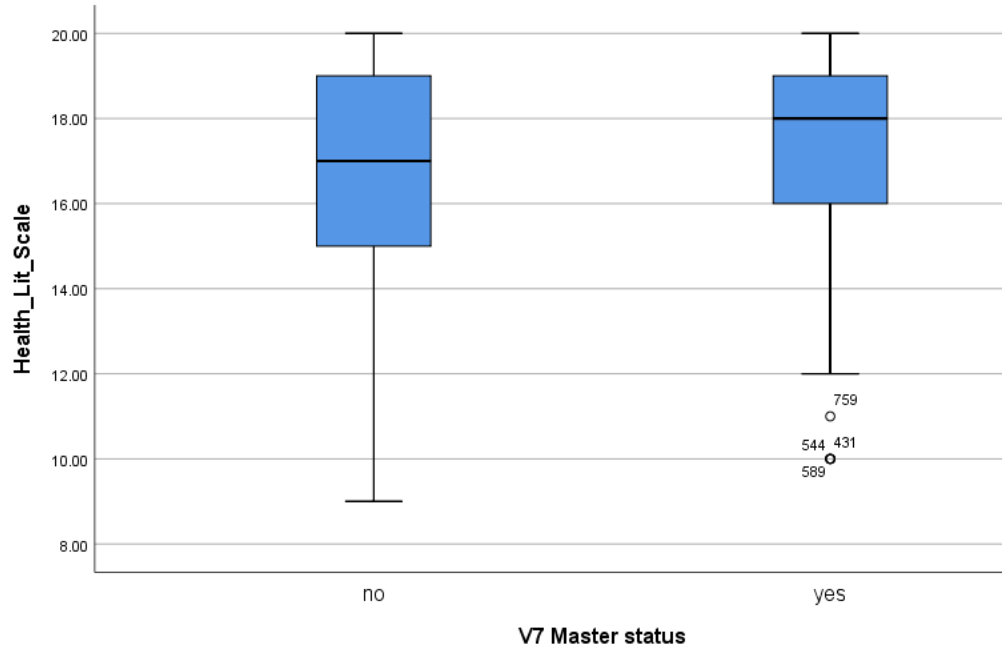


Figure A1: Boxplots of Health Literacy by Masters' Qualification

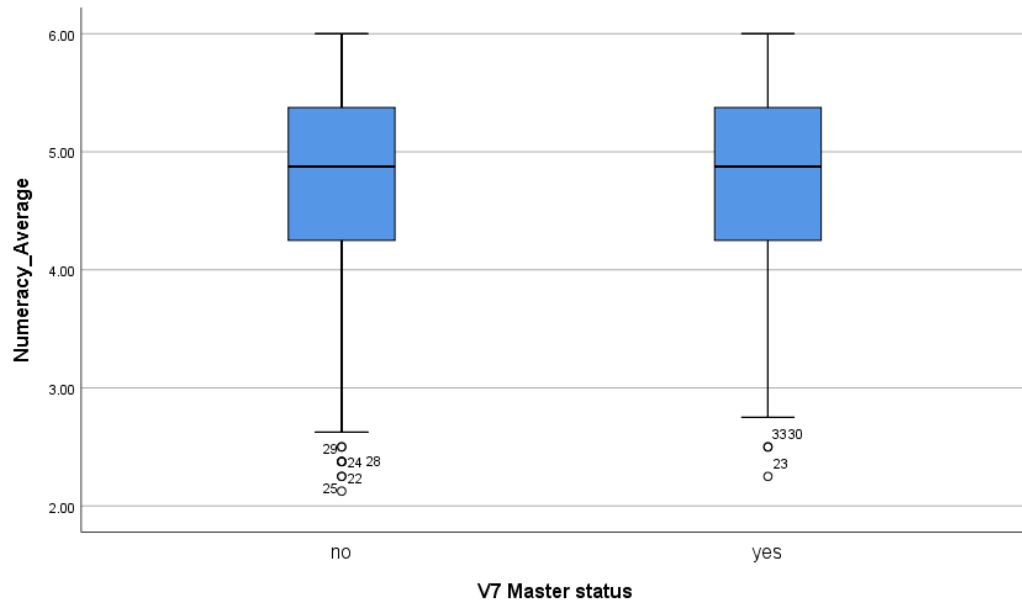


Figure A2: Boxplots of Numeracy by Masters' Qualification

Comparison of US Responders v. Non-US Responders

101 survey participants were identified as not being in the US at the time of their survey,

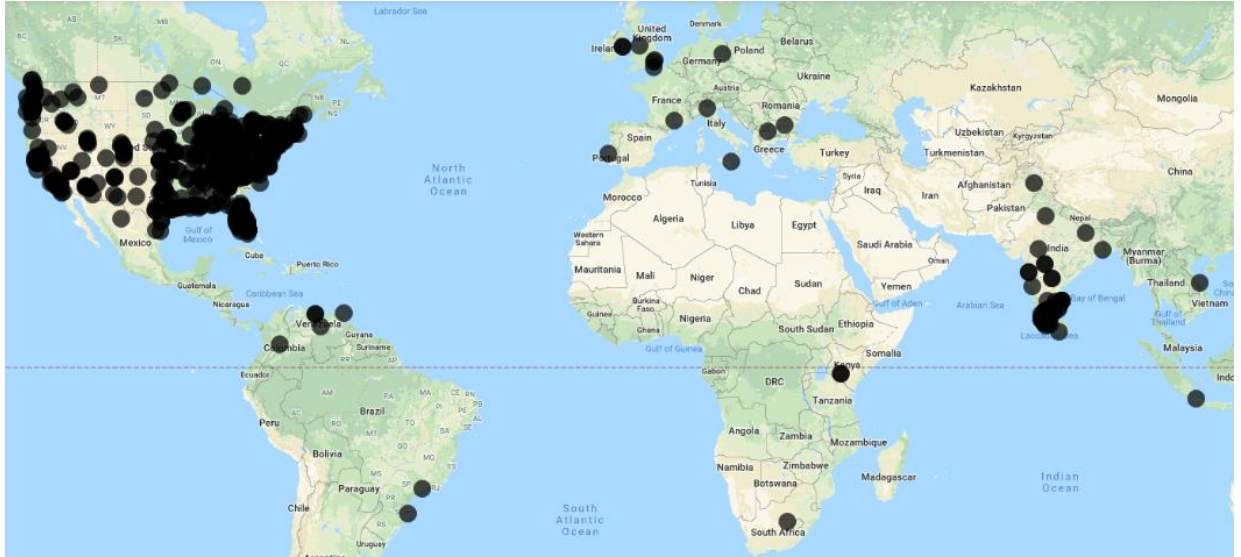


Figure A3: Map of participant location created using the latitude and longitude variables. Created by Travis Hyams using <https://www.darrinward.com/lat-long/> and used with permission

based on the geolocation variable automatically collected by Qualtrics (see **Figure A3**). Of these participants, 3 identified as black (3%), 25 as white (24.8%), 59 as Asian (58.4) and 14 as other (13.9%). These individuals differed significantly from US respondents, with non-US respondents being more likely to identify as Asians, Millennials and male, with low health literacy and low income. Because of these differences, non-US respondents were omitted for the analysis in Chapter 3, as the questions pertained to US-specific screening guidelines and methodologies, leaving a total sample size of 624 respondents for this analysis.

Variable Preparation

All variables included in this study were examined for: a) percentage of missing

data, b) frequency distribution, c) normal distribution, and d) outliers. Missing data are described above. If data were found to be non-normally distributed, a non-parametric test was instead chosen for bivariate analysis (for example, Mann-Whitney U Test rather than t-test), and Generalized Linear Models (GLIM) in SPSS was used for linear regression modeling, as GLIM does not have an assumption of normal distribution (Agresti, 2015). Data were visually examined for outliers by creating boxplots. Outliers were removed from analysis by calculating z-scores and removing data with z-scores ± 3 , as 99.7% of the data should be within three standard deviations of the mean. However, the need to remove outliers was overall minimal.

Finally, collinearity was assessed with correlation matrices. Where statistically significant correlation between two variables existed, decisions on which controls to keep in each model were made based on the following two criteria: (1) statistical association of the measure with the dependent variable and (2) importance of the measure to the model based on theory and previous research.

Interaction Effects for Analysis III

Estimated Marginal Means of Q37 On a scale of 0 (not at all sure) to 10 (completely sure) how sure are you that your answer to th...

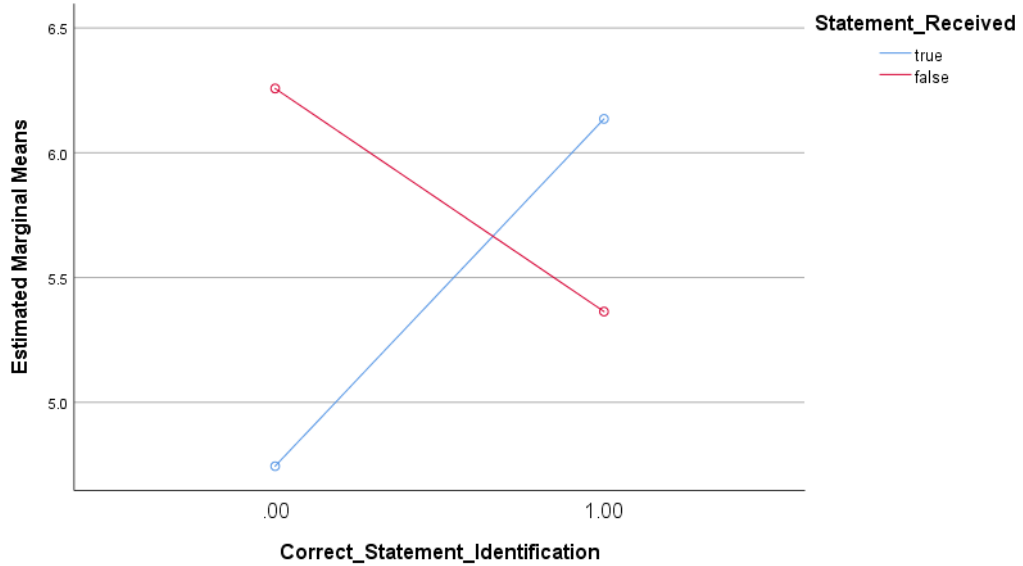


Figure A4: Interaction Effects of Statement Received (true or false) and Correct Identification of Results (0=incorrect, 1=correct). Dependent variable = Confidence in Response (Analysis III, Chapter 5).

Human Subjects Procedure

a. Informed Consent

All study activities were approved by the University of Maryland, College Park Institutional Review Board (IRB) (See **Appendix B**). A waiver of written informed consent and HIPAA was granted. Participants were provided with details of the study and possible risks and benefits, modeled on the University of Maryland Informed Consent Form template, in the description of the task. When Workers accepted the task, they were giving consent for the data to be used. To ensure anonymity of Workers to the best of our ability, the questionnaire was contained in Qualtrics, instead of within Amazon, and workers' information, besides geolocation, was not saved. After accepting the task, workers received an external link to the Qualtrics survey. Once the task was completed, Workers received a completion code to enter into MTurk to receive payment.

b. Compensation

Compensation for MTurk tasks, or HITs, is determined by the Requester. A frequently cited rule by workers is that work should be compensated at a rate of at least 10 cents per minute (MoneyPantry, 2017). For completing this approximately 15-minute questionnaire, Turkers were compensated at a rate of \$.20 per minute, for a total of \$3 per individual. In addition to this, Amazon charges a 25% fee, which includes a 5% fee for the use of individuals with Master Qualification, as well as \$.50 per participant for the Premium Qualification of specifying birth year range. Including the pilot study, the overall cost of this study was \$3724.80.

c. Funding

Funding for this study has very generously been provided by Dr. Barbara Curbow and the Department of Behavioral and Community Health.

Table A1: Questionnaire constructs and corresponding question numbers

Construct	Corresponding questions in survey	Source and Psychometrics
Health Literacy	Questions 2-5	<p>The BRIEF Health Literacy Screening Tool (Haun, Noland-Dodd, Graham-Pole, Rienzo, & Donaldson, 2009)</p> <p>Concurrent validity for the BRIEF was assessed and found to be acceptable:</p> <p>Pearson correlation results were:</p> <ul style="list-style-type: none"> • $r(378) = .40$ ($P < .01$) for the BRIEF and the REALM • $r(378) = .42$ ($P < .01$) for the BRIEF and the STOFHLA • $r(378) = .61$ ($P < .01$) for the REALM and the STOFHLA
Numeracy	Questions 6-13	<p>The Subjective Numeracy Scale (Fagerlin et al., 2007; Zikmund-Fisher et al., 2007)</p> <p>The SNS is both reliable and highly correlated with the Lipkus, Samsa & Rimer (2001) numeracy measure</p> <p>It has been validated in both risk communication and utility elicitation domains</p>
Perceived Susceptibility	Question 33	Adapted from the Health Information National Trends Survey (HINTS)
Perceived severity	Question 34	Adapted from the Health Information National Trends Survey (HINTS)
Perceived Importance of Screening	Question 35	Created by the study team
Knowledge of CRC screening	Question 14	Adapted from the Health Information National Trends Survey (HINTS)
Previous CRC screen	Question 16	Adapted from the Health Information National Trends Survey (HINTS)

Provider Relationship	Question 74 -77	Adapted from the Health Information National Trends Survey (HINTS)
Ability to Interpret Report	Question 23	Created by study team based on previous research
Demographics	Questions 74-89	Adapted from CDC measures and previously used by the research team

Appendix B: IRB Documentation

Appendix C: Questionnaire

Note: Headers were not visible to the person completing the questionnaire. Please use the following link to see the actual formatting of the questionnaire: [Mueller Survey Draft 9.25.17](#).

Intro

Q1 Hello!

This survey examines people's thoughts about cancer risk and related subjects. Please read each question carefully and answer truthfully.

We are looking for your honest and immediate responses to the information. We ask that you do not use any outside resources to help you answer the questions.

Also, you may learn new information as you go through the survey. Please do not go back to change your answers based on information you learn from the survey.

Thanks!

End of Block

Health Literacy

Q2 How confident are you filling out medical forms by yourself?

- Extremely (1)
- Quite a bit (2)
- Somewhat (3)
- A little bit (4)
- Not at all (5)

Q3 How often do you have someone help you read medical materials?

- Always (1)
- Often (2)

Occasionally (3)

Sometimes (4)

Never (5)

Q4 How often do you have problems learning about your medical condition because of difficulty understanding written information?

Always (1)

Often (2)

Occasionally (3)

Sometimes (4)

Never (5)

Q5 How often do you feel you don't understand what the doctor tells you?

Always (1)

Often (2)

Occasionally (3)

Sometimes (4)

Never (5)

End of Block

Subjective Numeracy

Q6 How good are you at working with fractions?

1 Not at all good (1)

2 (2)

3 (3)

- 4 (4)
- 5 (5)
- 6 Extremely good (6)

Q7 How good are you at working with percentages?

- 1 Not at all good (1)
- 2 (2)
- 3 (3)
- 4 (4)
- 5 (5)
- 6 Extremely good (6)

Q8 How good are you at calculating a 15% tip?

- 1 Not at all good (1)
 - 2 (2)
 - 3 (3)
 - 4 (4)
 - 5 (5)
 - 6 Extremely good (6)
-

Q9 How good are you at figuring out how much a shirt will cost if it is 25% off?

- 1 Not at all good (1)

- 2 (2)
- 3 (3)
- 4 (4)
- 5 (5)
- 6 Extremely good (6)

Q10 When reading the newspaper, how helpful do you find tables and graphs that are parts of a story?

- 1 Not at all helpful (1)
- 2 (2)
- 3 (3)
- 4 (4)
- 5 (5)
- 6 Extremely helpful (6)

Q11 When people tell you the chance of something happening, do you prefer that they use words ("it rarely happens") or numbers ("there's a 1% chance")?

- 1 Always prefer words (1)
- 2 (2)
- 3 (3)
- 4 (4)
- 5 (5)
- 6 Always prefer numbers (6)

Q12 When you hear a weather forecast, do you prefer predictions using percentages (e.g., “there will be a 20% chance of rain today”) or predictions using only words (e.g., “there is a small chance of rain today”)?

- 1 Always prefer percentages (1)
- 2 (2)
- 3 (3)
- 4 (4)
- 5 (5)
- 6 Always prefer words (6)

Q13 How often do you find numerical information to be useful?

- 1 Never (1)
- 2 (2)
- 3 (3)
- 4 (4)
- 5 (5)
- 6 Very often (6)

End of Block

Colon and rectal cancer

Q14 Which of these screening tests detect colon or rectal cancer? Check all that apply.

- Mammography (1)
- Colonoscopy (2)
- Pap Smear (3)

- Stool blood test (aka FOBT) (4)
- Prostate Specific Antigen (PSA) (5)
- Stool DNA test (6)
- Sigmoidoscopy (7)

Q15 Has a doctor ever recommended you to get a screening test to check for colon or rectal cancer?

- No (1)
- Yes (2)
- I don't know (3)

Q16 Have you ever had a screening test for colon or rectal cancer?

- No (1)
- Yes. Which one? (2) _____
- I don't know (3)

Q17 Which statement is closest to where you are now in your plans to get a screening test for colon or rectal cancer?

- I have already been tested (1)
- I am not thinking of getting tested (2)
- I think I need to consider getting tested (3)
- I think I should get tested but I'm not quite ready (4)
- I think I will probably get tested (5)
- I am committed to getting tested (6)

Q18 At what age should someone of average risk for colon or rectal cancer begin regular screening?

Q19 **Rank** the causes below from **very important (1) to not important (7)** in increasing the likelihood that you will develop colon or rectal cancer. Click on an answer and drag it into the position you think appropriate.

- _____ Behavior (1)
- _____ Character (2)
- _____ Social Environment (3)
- _____ Physical Environment (4)
- _____ Genetics (5)
- _____ Chance (6)
- _____ Society (7)

End of Block

Colonoscopy Reports

Q20 On the next page, you will be asked to read the results of a **fictional colonoscopy**. A colonoscopy is a medical procedure that examines your rectum and colon with a small scope. We then ask you to answer some questions about the information in the report. We are looking for your honest and immediate responses to the information. Again, please do not use any outside resources to help you answer the questions.

GIST Q21

These are the findings from your colonoscopy. They are separated into Findings, Impressions and Recommendations. The **Findings** will be useful for your primary care doctor or specialist. The **Impressions** summarize what we found today, and the **Recommendations** outline your next steps.

Findings

The perianal exam was abnormal. Findings included non-thrombosed external hemorrhoids. A multilobed non-obstruction large mass was found in the cecum, arising from the area of the appendiceal orifice. The mass was non-circumferential. The mass measured 5-6cm in its largest dimension. No bleeding was present. Biopsies taken with cold forceps for histology. A semi pedunculated polyp was found in transverse colon. The polyp was 10mm in size. The polyp was removed with hot snare. Resection and retrieval were complete. Estimated blood loss: none. A pedunculated non-bleeding polyp was found in the descending colon. The polyp was 12mm in

size. The polyp was removed with a hot snare. Resection and retrieval with a roth net were complete. Multiple small and large-mouthed diverticula were found in the entire colon. Non-bleeding internal hemorrhoids were found in retroflexion and were small.

Impressions

We found a mass in your colon and think it is cancer. We are running a test to see if it is cancer and will let you know as soon as we find out.

Your colon has small pouches which are inflamed or infected. This is a condition called Diverticulitis.

We also found hemorrhoids on both the inside and outside of your anus.

Recommendations

We have referred you to a colorectal surgeon. It is important that you see this surgeon as soon as possible.

Results about your mass will be sent to you in a few days. Be on the lookout for this in the mail.

You can go back to eating as you did before. However, a diet with lots of fiber and extra liquids (such as water) may help with your diverticulitis and hemorrhoids. Please talk to your doctor about this if you have concerns.

VERBATIM REPORT

Q22 These are the findings from your colonoscopy.

Findings

The perianal exam was abnormal. Findings included non-thrombosed external hemorrhoids. A multilobed non-obstruction large mass was found in the cecum, arising from the area of the appendiceal orifice. The mass was non-. The mass measured 5-6cm in its largest dimension. No bleeding was present. Biopsies taken with cold forceps for histology. A semi pedunculated polyp was found in transverse colon. The polyp was 10mm in size. The polyp was removed with hot snare. Resection and retrieval were complete. Estimated blood loss: none. A pedunculated non-bleeding polyp was found in the descending colon. The polyp was 12mm in size. The polyp was removed with a hot snare. Resection and retrieval with a roth net were complete. Multiple small and large-mouthed diverticula were found in the entire colon. Non-bleeding internal hemorrhoids were found in retroflexion and were small.

Impression

Cecal mass, likely malignant. Biopsied.

One 10mm polyp in transverse colon. Resected and retrieved.

One 12mm, non-bleeding polyp in descending colon. Resected and retrieved.

Diverticulitis in entire examined colon.

Internal and external hemorrhoids.

Recommendation

Referral to colorectal surgery.

Check CEA today.




Resume previous diet as tolerated.

Observe until discharge criteria are met.

Discharge home.

Await pathology results.

Q23 Please answer the questions below by moving the slider to the appropriate number.

How serious is this report? (4)	
How important is it that this patient follow up with a doctor? (5)	
To what extent is there a plan of care in place for this patient? (3)	

Q24 Please rank the following by how important it would be for you to have, with (1) indicating most important and (6) indicating least important.

- _____ A table or graph showing how my findings compare to normal findings (1)
- _____ The percentage of masses like this one that are cancerous (2)
- _____ The percentage of times that biopsy results like this are accurate (3)
- _____ Whether the doctor thinks this is cancer (4)
- _____ Whether the doctor thinks the situation is serious (5)
- _____ How much trust the doctor will have in the results of the biopsy (6)

Q25 If this colonoscopy report belonged to your parent, and he or she asked you what it meant, what would you say?

Q26 Please tell us why you would explain it that way.

Q27 Think about the recommendations the doctor gave you in the report. How would you describe the wording of the recommendations?

- It was written in medical language (1)
- It was written in plain language (2)

Q28 A1 and A2 Cancer statement

*Q28 Please read the summary below about **colon cancer rates** and answer the questions on the next page. You can use the red back button to return to the statement at any time.*

From the mid-1980s through 2013, colon cancer rates:

declined in adults age 55 years and older

increased by 2.4% per year in adults 20 to 29 years

increased by 1% per year in adults age 30 to 39 years

Q29 Please read the summary below about colon cancer rates and answer the questions on the next page. You can use the red back button to return to the statement at any time.

From the mid-1980s through 2013, colon cancer rates:

increased in adults age 55 years and older

declined by 2.4% per year in adults 20 to 29 years

declined by 1% per year in adults age 30 to 39 years.

End of Block

Cancer Statement A1 and A2



Q30 What do these data say is happening to colon cancer in the US?

Q31 Do you think the statement about colon cancer is true or false?

True (1)

False (2)

Q32 On a scale of 0 (not at all sure) to 10 (completely sure) how sure are you that your answer to the last question is correct? *Please move the slider to indicate your choice.*



0 (0)

1 (1)

2 (2)

3 (3)

4 (4)

5 (5)

6 (6)

7 (7)

8 (8)







9 (9)

10 (10)






End of Block

Risk of cancer

Q33 How likely do you think it is that you will develop any of the cancers listed below in your lifetime? Please be sure to indicate the likelihood for each type of cancer by moving the slider to the right.

Skin (1)	
Lung (2)	
Human-Papilloma (HPV) Related (anal, penile, cervical or head and neck) (3)	
Colon or Rectal (4)	
Breast (5)	
Any Type (6)	

Q34 If diagnosed with advanced stage cancer, how likely do you think it is that you would die from any of the cancers listed below? Please be sure to indicate the likelihood for each type of cancer by moving the slider to the right.

Skin (1)	
Lung (2)	
Human-Papilloma (HPV) Related (anal, penile, cervical or head and neck) (3)	
Colon or Rectal (4)	
Breast (5)	

Any Type (6)	
--------------	--

Q35 How important is it that **you are screened for any of the types of cancer** listed below in your lifetime? *Please be sure to indicate the importance for each type of cancer by moving the slider to the right.*

Skin (1)	
Lung (2)	
Human-Papilloma (HPV) Related (anal, penile, cervical or head and neck) (3)	
Colon or Rectal (4)	
Breast (5)	
Any Type (6)	

Q36 Have you ever been diagnosed with cancer?

- No (1)
- Yes. What type? (2) _____

Q37 Have you ever been diagnosed with a pre-cancerous condition?

- No (1)
- Yes. On what location on body, or what type of cancer? (2)

- I don't know (3)

Q38 Has anyone in your family ever been diagnosed with cancer?

- No (1)
- Yes. Who, and what type of cancer? (2)
-

I don't know (3)

Q39 Has anyone close to you died of cancer?

- No (1)
- Yes. Who, and what type of cancer? (2)
-

I don't know (3)

Q40 Has cancer impacted your life in any other way?

- No (1)
- Yes. How so? (2) _____

Genetic Questions

Q41 Researchers have found that some people have distinct genetic changes, also referred to as mutations. These mutations may raise a person's risk for some types of cancer. When someone is at risk, they are often referred to as having "**positive mutation status**", meaning they carry that mutation.

Q42 Have you ever had a **genetic test** to check your mutation status that was conducted by a **medical professional**?

- No (1)
- Yes (2)
- I don't know (3)

Q43 What was your test result?

Positive mutation status. Type of cancer(s): (1)

Negative mutation status. Type of cancer(s): (2)

Uninformative/Indeterminate/Inconclusive (3)

I prefer not to answer (4)

I don't know (5)

Q44 Have you ever had a **direct to consumer genetic test** (for example, 23andMe). In other words, **you sent a sample of DNA to a private company** and you received information about your DNA?

No (1)

Yes (2)

I don't know (3)

Q45 Did your direct to consumer genetic test provide information about your cancer mutation status?

No (1)

Yes. About what type of cancer(s)? (2)

I prefer not to answer (3)

I don't know (4)

Q46 What was your test result?

Positive mutation status. What type of cancers? (1)

Negative mutation status. What type of cancers? (2)

Uninformative/Indeterminate/Inconclusive (3)

I prefer not to answer (4)

I don't know (5)

Q47 To what extent do you believe it is ethical to provide cancer risk data to people?

(1) not at all likely (10) very likely (1)



Evaluation Of Treatment Strategies To Reduce Drug Craving And Harm In People With Opioid Use Disorder Protocol Development And Implementation Task Order

End of Block

Social Desirability

Q48 I am always courteous even to people who are disagreeable.

Definitely true (1)

Mostly true (2)

Don't know (3)

Mostly false (4)

Definitely false (5)

Q49 There have been occasions when I took advantage of someone.

Definitely true (1)

Mostly true (2)

Don't know (3)

- Mostly false (4)
- Definitely false (5)

Q50 I sometimes try to get even rather than forgive and forget.

- Definitely true (1)
- Mostly true (2)
- Don't know (3)
- Mostly false (4)
- Definitely false (5)

Q51 I sometimes feel resentful when I don't get my way.

- Definitely true (1)
- Mostly true (2)
- Don't know (3)
- Mostly false (4)
- Definitely false (5)

Q52 No matter who I'm talking to, I'm always a good listener.

- Definitely true (1)
- Mostly true (2)
- Don't know (3)
- Mostly false (4)
- Definitely false (5)

Social Isolation

Q53 I experience a general sense of emptiness.

- Yes! (1)
- Yes (2)
- More or less (3)
- No (4)
- No! (5)

Q54 I miss having people around.

- Yes! (1)
- Yes (2)
- More or less (3)
- No (4)
- No! (5)

Q55 I often feel rejected.

- Yes! (1)
- Yes (2)
- More or less (3)
- No (4)
- No! (5)

Q56 There are plenty of people I can rely on when I have problems.

- Yes! (1)
- Yes (2)
- More or less (3)
- No (4)
- No! (5)

Q57 There are many people I can trust completely.

- Yes! (1)
- Yes (2)
- More or less (3)
- No (4)
- No! (5)

Q58 There are enough people I feel close to.

- Yes! (1)
- Yes (2)
- More or less (3)
- No (4)
- No! (5)

End of Block

PC Questions

Q59 On an average **weekday**, about how many hours do you spend in the **physical** presence of other people?

Q60 On an average **weekday**, about how many hours do you spend in the **virtual** (online) presence of other people?

Q61 On an average **weekend day**, about how many hours do you spend in the **physical** presence of other people?

Q62 On an average **weekend day**, about how many hours do you spend in the **virtual** presence of other people?

General Health

Q63 In general, how would you describe your health?

- Excellent (1)
- Very good (2)
- Good (3)
- Fair (4)
- Poor (5)
- Very poor (6)

Q64 Now thinking about your **physical health**, which includes physical illness and injury, for how many days during the past 30 days was your physical health **not good**?

Q65 Now thinking about your **mental health**, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health **not good**?

Q66 During the past **30 days**, for about how many days did **poor physical or mental health** keep you from doing your usual activities, such as self-care, work, or recreation?

Q67 During the past 30 days, **for about how many days did pain** make it hard for you to do your usual activities, such as self-care, work, or recreation?

Q68 Do you have a primary medical provider you see at least once a year?

- No (1)
- Yes (2)

Q69 How would you describe your relationship with this provider?

- Excellent (6)
- Very good (5)
- Good (4)
- Fair (3)
- Poor (2)
- Very poor (1)

Q70 Please tell us why you would describe your relationship that way.

Q71 Do you have health insurance?

- No (1)
- Yes (2)

Q72 How would you rate the quality of your health insurance?

- Excellent (6)
- Very good (5)
- Good (4)
- Fair (3)
- Poor (2)
- Very poor (1)

Q73 Please tell us why you would rate your insurance this way.

End of Block

Demographics

Q74 With which gender do you identify?

- Female (1)
- Male (2)
- Other (3) _____

Q75 How old were you on your last birthday?

Q76 Are you of Hispanic or Latino descent?

- No (1)
- Yes (2)

Q77 With what race do you identify?

- White/Caucasian (1)
- Black/African American (2)
- American Indian or Alaskan Native (3)
- Asian/Asian American (4)
- Native Hawaiian/Pacific Islander (5)
- Other (6) _____

Q78 About how many hours a week do you work for MTurk or in similar jobs?

Q79 Other than MTurk and similar jobs, are you employed for pay?

- Yes, full-time (1)
- Yes, part-time (2)
- No, I'm disabled (3)
- No, I'm retired (4)
- No, I'm looking for work (5)
- No, MTurk or similar jobs are my only jobs (6)
- I'm a homemaker (7)
- Other (8) _____

Q80 Are you currently attending school?

- No (1)

- Yes, college (2)
 - Yes, graduate or professional school (3)
 - Yes, other: (4) _____
-

Q81 Do you routinely care for another person who has a disability, serious illness or advanced age?

- No (1)
 - Yes. For how many hours a week? (2)
-

Q82 What is your relationship to this person? He/she is...

- My grandparent (1)
 - My parent (2)
 - My child. How old is this child? (3)
-
- My spouse or partner (4)
 - Other (5) _____

Q83 Do you consider yourself the primary caregiver for this person?

- No (1)
- Yes (2)

Q84 How much **stress** does routinely caring for this person cause you? ***Please indicate your choice by moving the slider to the appropriate number. 1 indicates no stress, 10 indicates high stress.***

Emotional stress (1)	
Physical stress (2)	
Financial stress (3)	

Q85 What is your marital status?

- Married/legal domestic partnership (1)
- Living with partner (2)
- Divorced (3)
- Widowed (4)
- Single (5)
- Other (6) _____

Q86 Do you have dependent children under the age of 18 living with you?

- No (1)
- Yes (2)

Q87 What is the **highest grade of school** you have completed? Please move the slider to the appropriate number.

- Elementary (0-8)
- High School (9-12)
- GED (12)
- College (13-16)
- Graduate School or above (17)

Please indicate the highest year (1)	
--------------------------------------	--

Q88 Please estimate your yearly household income.

- less than \$10,000 (1)
- \$10,000-\$19,999 (2)
- \$20,000-\$29,999 (3)
- \$30,000-\$39,999 (4)
- \$40,000-\$49,999 (5)
- \$50,000-\$59,999 (6)
- \$60,000-\$69,999 (7)
- \$70,000-\$79,999 (8)
- 80,000-\$89,999 (9)
- \$90,000-\$99,999 (10)
- \$100,000 or above (11)

Q89 How many people **including yourself** are supported on this income?

Appendix D: MTurk Interface

Coding

<div>The University of Maryland requests the below task to be completed. The task consists of a survey which will take about 15 minutes to complete. The compensation for this task is \$3.00.</div>

<div> </div>

<div>The survey will ask questions about your experience with health and health care, and will ask you to interpret some medical information. There are no right or wrong answers to any of the questions.</div>

<div> </div>

<div>This task is being requested by researchers in the School of Public Health at the University of Maryland, College Park. There are no known risks to participating in this task. Any answers you provide as part of this task will be kept confidential to the best of our ability and not shared with Amazon. Any potential loss of confidentiality will be minimized by using Qualtrics, not Amazon, to collect and store data; by storing the final data on a secure UMD drive, to which only the research team has access.</div>

<div> </div>

<div>If we write a report or article about this task, your identity will be protected to the maximum extent possible. <div> Your information may be shared with representatives of the University of Maryland, College Park or governmental authorities if you or someone else is in danger or if we are required to do so by law.</div>

<div> </div>

<div>Your participation in this task is completely voluntary. You may choose not to take part at all. <div> If you decide to participate in this task, you may stop participating at any time. <div> If you decide not to participate in this study or if you stop participating at any time, you will not receive payment for the task.</div>

If you decide to stop taking part in the study, if you have questions, concerns, or complaints, or if you need to report an injury related to the task, please contact the investigator:

Nora Mueller

Department of Behavioral and Community Health

School of Public Health

University of Maryland, College Park 20742

nmueller@umd.edu

[\(703\) 581-5285](tel:(703)581-5285 "Call via Hangouts")

If you have questions about your rights as a participant or wish to report a task-related injury, please contact:

University of Maryland College Park

Institutional Review Board Office

1204 Marie Mount Hall

College Park, Maryland, 20742

E-mail: irb@umd.edu

<div>Telephone: 301-405-0678</div>

<div> </div>

<div>This task has been reviewed according to the University of Maryland, College Park IRB procedures for research involving human subjects.</div>

<div>By accepting this task, you indicate that you are at least 18 years of age; you have read this form or have had it read to you; your questions have been answered to your satisfaction and you voluntarily agree to participate.</div>

<div> </div>

<div> </div>

<div class="row" id="workContent">

<div class="col-xs-12 col-md-6 col-md-offset-3"><!-- Content for Worker -->

<table class="table table-condensed table-bordered">

<colgroup>

<col class="col-xs-4 col-md-4" />

<col class="col-xs-8 col-md-8" />

</colgroup>

<tbody>

<tr>

<td><label>Survey link:</label></td>

<td><a class="dont-break-out"

href="http://[https://umdsurvey.umd.edu/jfe/form/SV_50dvn2RAhzxFbjT]"

target="_blank">https://umdsurvey.umd.edu/jfe/form/SV_50dvn2RAhzxFbjT</td>

</tr>

</tbody>

</table>

<!-- End Content for Worker --><!-- Input from Worker -->

<div class="form-group"><label for="surveycode">Provide the survey code here:</label>

```
<input class="form-control" id="surveycode" name="surveycode" placeholder="e.g. 123456"
required="" type="text" /> <!-- End input from Worker --></div>
```

```
</div>
```

```
</div>
```

MTurk Interface

The University of Maryland requests the below task to be completed. The task consists of a survey which will take about 15 minutes to complete. The compensation for this task is \$3.00.

The survey will ask questions about your experience with health and health care and will ask you to interpret some medical information. There are no right or wrong answers to any of the questions.

This task is being requested by researchers in the School of Public Health at the University of Maryland, College Park. There are no known risks to participating in this task. Any answers you provide as part of this task will be kept confidential to the best of our ability and not shared with Amazon. Any potential loss of confidentiality will be minimized by using Qualtrics, not Amazon, to collect and store data and by storing the final data on a secure UMD drive, to which only the research team has access.

If we write a report or article about this task, your identity will be protected to the maximum extent possible. Your information may be shared with representatives of the University of Maryland, College Park or governmental authorities if you or someone else is in danger or if we are required to do so by law.

Your participation in this task is completely voluntary. You may choose not to take part at all. If you decide to participate in this task, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not receive payment for the task.

If you decide to stop taking part in the study, if you have questions, concerns, or complaints, or if you need to report an injury related to the task, please contact the investigator:

Nora Mueller

Department of Behavioral and Community Health

School of Public Health

University of Maryland, College Park 20742

nmueller@umd.edu

(703) 581-5285

If you have questions about your rights as a participant or wish to report a task-related injury, please contact:

University of Maryland College Park
Institutional Review Board Office
1204 Marie Mount Hall
College Park, Maryland, 20742
E-mail: irb@umd.edu
Telephone: 301-405-0678

This task has been reviewed according to the University of Maryland, College Park IRB procedures for research involving human subjects.

By accepting this task, you indicate that you are at least 18 years of age; you have read this form or have had it read to you; your questions have been answered to your satisfaction and you voluntarily agree to participate.

Survey link: https://umdsurvey.umd.edu/jfe/form/SV_50dnv2RAhzxFbjT

Provide the survey code here:

References

- . (2007).
- ACS. (2017a). American Cancer Society Recommendations for Colorectal Cancer Early Detection. Retrieved from <https://www.cancer.org/cancer/colon-rectal-cancer/detection-diagnosis-staging/acs-recommendations.html>
- ACS. (2017b). *Colorectal Cancer Fact & Figures 2017-2019*. Atlanta: American Cancer Society.
- ACS. (2017c). The Cost of Cancer. *American Cancer Society Cancer Action Network Public Policy Resource*. doi:<https://www.acscan.org/policy-resources/costs-cancer>
- Adams, R. J., Smith, B. J., & Ruffin, R. E. (2001). Patient preferences for autonomy in decision making in asthma management. *Thorax*, *56*(2), 126-132. doi:10.1136/thorax.56.2.126
- Agresti, A. (2015). *Foundations of Linear and Generalized Linear Models*. Hoboken, NJ: John Wiley & Sons.
- AHRQ. (2016). Total Expenses and Percent Distribution for Selected Conditions by Source of Payment: United States, 2014. *Medical Expenditure Panel Survey Household Component Data, Generated Interactively*.
- Al Sayah, F., Majumdar, S. R., Williams, B., Robertson, S., & Johnson, J. A. (2013). Health literacy and health outcomes in diabetes: a systematic review. *J Gen Intern Med*, *28*(3), 444-452. doi:10.1007/s11606-012-2241-z
- Alberti, L. R., Garcia, D. P. C., Coelho, D. L., De Lima, D. C. A., & Petroianu, A. (2015). How to improve colon cancer screening rates. *World Journal of Gastrointestinal Oncology*, *7*(12), 484-491. doi:10.4251/wjgo.v7.i12.484
- Allen, S. V., Solberg Nes, L., Marnach, M. L., Polga, K., Jenkins, S. M., Files, J. A., . . . Pruthi, S. (2012). Patient understanding of the revised USPSTF screening mammogram guidelines: need for development of patient decision aids. *BMC Women's Health*, *12*(1), 36. doi:10.1186/1472-6874-12-36
- America's Health Literacy: Why we Need Accessible Health Information. An Issue Brief from the U.S. Department of Health and Human Services. (2008).
- Araghi, M., Fidler, M. M., Arnold, M., Jemal, A., Bray, F., & Soerjomataram, I. (2018). The Future Burden of Colorectal Cancer Among US Blacks and Whites. *JNCI: Journal of the National Cancer Institute*, *110*(7), 791-793. doi:10.1093/jnci/djx287
- ASGE. (2014). Colorectal Cancer Screening [Press release]
- Atkin, W. S., Edwards, R., Kralj-Hans, I., Wooldrage, K., Hart, A. R., Northover, J. M. A., . . . Cuzick, J. (2010). Once-only flexible sigmoidoscopy screening in prevention of colorectal cancer: a multicentre randomised controlled trial. *The Lancet*, *375*(9726), 1624-1633. doi:[https://doi.org/10.1016/S0140-6736\(10\)60551-X](https://doi.org/10.1016/S0140-6736(10)60551-X)
- Augustus, G. J., & Ellis, N. A. (2018). Colorectal Cancer Disparity in African Americans: Risk Factors and Carcinogenic Mechanisms. *Am J Pathol*, *188*(2), 291-303. doi:10.1016/j.ajpath.2017.07.023
- Aune, D., Chan, D. S. M., Lau, R., Vieira, R., Greenwood, D. C., Kampman, E., & Norat, T. (2011). Dietary fibre, whole grains, and risk of colorectal cancer: systematic review and dose-response meta-analysis of prospective studies. *BMJ*, *343*. doi:10.1136/bmj.d6617
- Baker, D. W., Parker, R. M., Williams, M. V., Clark, W. S., & Nurss, J. (1997). The relationship of patient reading ability to self-reported health and use of health services. *Am J Public Health*, *87*(6), 1027-1030.
- Baron, R. C., Rimer, B. K., Breslow, R. A., Coates, R. J., Kerner, J., Melillo, S., . . . Briss, P. A. (2008). Client-Directed Interventions to Increase Community Demand for Breast, Cervical, and Colorectal Cancer Screening: A Systematic Review. *American Journal of Preventive Medicine*, *35*(1, Supplement), S34-S55. doi:<http://dx.doi.org/10.1016/j.amepre.2008.04.002>

- Basch, C. H., Basch, C. E., Zybert, P., & Wolf, R. L. (2016). Fear as a Barrier to Asymptomatic Colonoscopy Screening in an Urban Minority Population with Health Insurance. *Journal of Community Health, 41*(4), 818-824. doi:10.1007/s10900-016-0159-9
- Batterham, R. W., Hawkins, M., Collins, P. A., Buchbinder, R., & Osborne, R. H. (2016). Health literacy: applying current concepts to improve health services and reduce health inequalities. *Public Health, 132*, 3-12. doi:<https://doi.org/10.1016/j.puhe.2016.01.001>
- Bentley, F. R., Daskalova, N., & White, B. (2017). *Comparing the Reliability of Amazon Mechanical Turk and Survey Monkey to Traditional Market Research Surveys*. Paper presented at the Proceedings of the 2017 CHI Conference Extended Abstracts on Human Factors in Computing Systems, Denver, Colorado, USA.
- Berinsky, A. J., Huber, G. A., & Lenz, G. S. (2012). Evaluating Online Labor Markets for Experimental Research: Amazon.com's Mechanical Turk. *Political Analysis, 20*(3), 351-368.
- Berkman, N. D., Sheridan, S. L., Donahue, K. E., Halpern, D. J., Viera, A., Crotty, K., . . . Viswanathan, M. (2011). Health literacy interventions and outcomes: an updated systematic review. *Evid Rep Technol Assess (Full Rep)*(199), 1-941.
- Bjorklund, D. F., & Buchanan, J. J. (1989). Developmental and knowledge base differences in the acquisition and extension of a memory strategy. *Journal of Experimental Child Psychology, 48*(3), 451-471. doi:[http://dx.doi.org/10.1016/0022-0965\(89\)90052-0](http://dx.doi.org/10.1016/0022-0965(89)90052-0)
- Blalock, S. J., & Reyna, V. F. (2016). Using fuzzy-trace theory to understand and improve health judgments, decisions, and behaviors: A literature review. *Health psychology : official journal of the Division of Health Psychology, American Psychological Association, 35*(8), 781-792. doi:10.1037/hea0000384
- Borges, N. J., Manuel, R. S., Elam, C. L., & Jones, B. J. (2006). Comparing millennial and generation X medical students at one medical school. *Acad Med, 81*(6), 571-576. doi:10.1097/01.acm.0000225222.38078.47
- Borges, N. J., Manuel, R. S., Elam, C. L., & Jones, B. J. (2010). Differences in motives between Millennial and Generation X medical students. *Med Educ, 44*(6), 570-576. doi:10.1111/j.1365-2923.2010.03633.x
- Brown, M. T., & Bussell, J. K. (2011). Medication adherence: WHO cares? *Mayo Clin Proc, 86*(4), 304-314. doi:10.4065/mcp.2010.0575
- Buhrmester, M., Kwang, T., & Gosling, S. D. (2011). Amazon's Mechanical Turk. *Perspectives on Psychological Science, 6*(1), 3-5. doi:10.1177/1745691610393980
- Campos, F. G. (2017). Colorectal cancer in young adults: A difficult challenge. *World journal of gastroenterology, 23*(28), 5041-5044. doi:10.3748/wjg.v23.i28.5041
- Cancer Facts & Figures 2013: Atlanta: American Cancer Society; 2013
- CDC. (2013). Retrieved from <http://www.cdc.gov/cancer/colorectal/statistics/race.htm>
- Carcaise-Edinboro, P., & Bradley, C. J. (2008). Influence of Patient-Provider Communication on Colorectal Cancer Screening. *Med Care, 46*(7), 738-745. doi:10.1097/MLR.0b013e318178935a
- Cassese, E. C., Huddy, L., Hartman, T. K., Mason, L., & Weber, C. R. (2013). Socially Mediated Internet Surveys: Recruiting Participants for Online Experiments. *PS: Political Science and Politics, 46*(4), 775-784.
- CDC. (2019). Colorectal Cancer Screening Rates.
- Chandler, J., & Shapiro, D. (2016). Conducting Clinical Research Using Crowdsourced Convenience Samples. *Annu Rev Clin Psychol, 12*, 53-81. doi:10.1146/annurev-clinpsy-021815-093623
- Chew, L. D., Bradley, K. A., & Boyko, E. J. (2004). Brief questions to identify patients with inadequate health literacy. *Fam Med, 36*(8), 588-594.

- Cho, R. N., Plunkett, B. A., Wolf, M. S., Simon, C. E., & Grobman, W. A. (2007). Health literacy and patient understanding of screening tests for aneuploidy and neural tube defects. *Prenatal Diagnosis*, 27(5), 463-467. doi:10.1002/pd.1712
- Clouston, S. A. P., Rubin, M. S., Chae, D. H., Freese, J., Nemesure, B., & Link, B. G. (2017). Fundamental causes of accelerated declines in colorectal cancer mortality: Modeling multiple ways that disadvantage influences mortality risk. *Social Science & Medicine*, 187(Supplement C), 1-10. doi:<https://doi.org/10.1016/j.socscimed.2017.06.013>
- Coleman, C., Kurtz-Rossi, S., & McKinney, J. (2009). Calgary Charter on Health Literacy.
- Cornett, S. (2009). Assessing and Addressing Health Literacy. *OJIN: The Online Journal of Issues in Nursing*, 14(3).
- Curbow, B., King-Marshall, E., Mueller, N., Sultan, S., & George, T. (under review). Social vs. practical problems in attaining a colonoscopy: Different profiles?
- Curbow, B. A., Dailey, A. B., King-Marshall, E. C., Barnett, T. E., Schumacher, J. R., Sultan, S., & George, T. J., Jr. (2015). Pathways to colonoscopy in the South: seeds of health disparities. *Am J Public Health*, 105(4), e103-111. doi:10.2105/ajph.2014.302347
- Cutilli, C. C., & Bennett, I. M. (2009). Understanding the Health Literacy of America Results of the National Assessment of Adult Literacy. *Orthopaedic nursing / National Association of Orthopaedic Nurses*, 28(1), 27-34. doi:10.1097/01.NOR.0000345852.22122.d6
- Davis, D. M., Marcet, J. E., Frattini, J. C., Prather, A. D., Mateka, J. J., & Nfonsam, V. N. (2011). Is it time to lower the recommended screening age for colorectal cancer? *J Am Coll Surg*, 213(3), 352-361. doi:10.1016/j.jamcollsurg.2011.04.033
- Davis, T. C., Dolan, N. C., Ferreira, M. R., Tomori, C., Green, K. W., Sipler, A. M., & Bennett, C. L. (2001). The role of inadequate health literacy skills in colorectal cancer screening. *Cancer Invest*, 19(2), 193-200.
- Davis, T. C., Williams, M. V., Marin, E., Parker, R. M., & Glass, J. (2002). Health literacy and cancer communication. *CA Cancer J Clin*, 52(3), 134-149.
- Deen, K. I., Silva, H., Deen, R., & Chandrasinghe, P. C. (2016). Colorectal cancer in the young, many questions, few answers. *World J Gastrointest Oncol*, 8(6), 481-488. doi:10.4251/wjgo.v8.i6.481
- DeMaria, J., & Hoffman, C. (2016). *Generational Influences on Patient Perspectives Impacting Patient Engagement*. Paper presented at the Healthcare Information and Management Systems Society, Las Vegas.
- Difallah, D. E., Catasta, M., Demartini, G., Ipeirotis, P. G., Cudr, P., #233, & -Mauroux. (2015). *The Dynamics of Micro-Task Crowdsourcing: The Case of Amazon MTurk*. Paper presented at the Proceedings of the 24th International Conference on World Wide Web, Florence, Italy.
- Dreyfuss, E. (2018, 08.18.2018). A Bot Panic Hits Amazon's Mechanical Turk. *Wired*.
- Edwards, B. K., Ward, E., Kohler, B. A., Ehemann, C., Zauber, A. G., Anderson, R. N., . . . Ries, L. A. G. (2010a). Annual report to the nation on the status of cancer, 1975-2006, featuring colorectal cancer trends and impact of interventions (risk factors, screening, and treatment) to reduce future rates. *Cancer*, 116(3), 544-573. doi:10.1002/cncr.24760
- Edwards, B. K., Ward, E., Kohler, B. A., Ehemann, C., Zauber, A. G., Anderson, R. N., . . . Ries, L. A. G. (2010b). Annual Report to the Nation on the Status of Cancer, 1975–2006, Featuring Colorectal Trends and Impact of Interventions (Risk Factors, Screening, and Treatment) to Reduce Future Rates. *Cancer*, 116(3), 544-573. doi:10.1002/cncr.24760
- Fagerlin, A., Zikmund-Fisher, B. J., Ubel, P. A., Jankovic, A., Derry, H. A., & Smith, D. M. (2007). Measuring numeracy without a math test: development of the Subjective Numeracy Scale. *Med Decis Making*, 27(5), 672-680. doi:10.1177/0272989x07304449
- Forsberg, A. M., Hagel, E., Jaramillo, E., Rubio, C. A., Bjorck, E., & Lindblom, A. (2015). Predicting Outcome in Colonoscopic High-risk Surveillance. *Anticancer Res*, 35(9), 4813-4819.

- Fox, S., & Duggan, M. (2012). Mobile Health 2012. Retrieved from http://www.pewinternet.org/files/oldmedia//Files/Reports/2012/PIP_MobileHealth2012_FINAL.pdf.
- Gallagher, L., McAuley, J., & Moseley, G. L. (2013). A randomized-controlled trial of using a book of metaphors to reconceptualize pain and decrease catastrophizing in people with chronic pain. *Clin J Pain, 29*(1), 20-25. doi:10.1097/AJP.0b013e3182465cf7
- Giaj Levra, N., Cuniberti, F. A., Rava, A., Vietti, G., & Sciascia, S. (2012). Health Literacy and Discharge Instruction Adherence. *Journal of General Internal Medicine, 27*(3), 273-273. doi:10.1007/s11606-011-1969-1
- Goodman, J. K., Cryder, C. E., & Cheema, A. (2013). Data Collection in a Flat World: The Strengths and Weaknesses of Mechanical Turk Samples. *Journal of Behavioral Decision Making, 26*(3), 213-224. doi:10.1002/bdm.1753
- Graham, S., & Brookey, J. (2008). Do patients understand? *The Permanente journal, 12*(3), 67-69.
- Gurmankin, A. D., Baron, J., & Armstrong, K. (2004). Intended Message Versus Message Received in Hypothetical Physician Risk Communications: Exploring the Gap. *Risk Analysis, 24*(5), 1337-1347. doi:10.1111/j.0272-4332.2004.00530.x
- Ha, J. F., & Longnecker, N. (2010). Doctor-Patient Communication: A Review. *The Ochsner Journal, 10*(1), 38-43.
- Haggar, F. A., & Boushey, R. P. (2009). Colorectal Cancer Epidemiology: Incidence, Mortality, Survival, and Risk Factors. *Clinics in Colon and Rectal Surgery, 22*(4), 191-197. doi:10.1055/s-0029-1242458
- Hanoch, Y. (2004). Improving Doctor-Patient Understanding of Probability in Communicating Cancer-Screening Test Findings. *Journal of Health Communication, 9*(4), 327-335. doi:10.1080/10810730490468496
- Hassan, C., Rossi, P. G., Camilloni, L., Rex, D. K., Jimenez-Cendales, B., Ferroni, E., . . . Group, H. (2012). Meta-analysis: adherence to colorectal cancer screening and the detection rate for advanced neoplasia, according to the type of screening test. *Alimentary Pharmacology & Therapeutics, 36*(10), 929-940. doi:doi:10.1111/apt.12071
- Haun, J., Noland-Dodd, V., J, Graham-Pole, J., Rienzo, B., & Donaldson, P. (2009). Testing the BRIEF Health Literacy Screening Tool. *The Federal Practitioner*.
- Herber, O. R., Gies, V., Schwappach, D., Thürmann, P., & Wilm, S. (2014). Patient information leaflets: informing or frightening? A focus group study exploring patients' emotional reactions and subsequent behavior towards package leaflets of commonly prescribed medications in family practices. *BMC Family Practice, 15*(1), 163. doi:10.1186/1471-2296-15-163
- Hesse, B., & Moser, R. (2018). *Health Information National Trends Survey (HINTS), 2018*.
- Holt, C. L., Litaker, M. S., Scarinci, I. C., Debnam, K. J., McDavid, C., McNeal, S. F., . . . Martin, M. Y. (2013). Spiritually based intervention to increase colorectal cancer screening among African Americans: screening and theory-based outcomes from a randomized trial. *Health Educ Behav, 40*(4), 458-468. doi:10.1177/1090198112459651
- IOM. (2003). Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care. In S. BD, S. AY, & N. AR (Eds.), *RACIAL AND ETHNIC DISPARITIES IN DIAGNOSIS AND TREATMENT: A REVIEW OF THE EVIDENCE AND A CONSIDERATION OF CAUSES*. Washington, DC: National Academies Press (US).
- Ipeirotis, P. G. (2010a). Analyzing the Amazon Mechanical Turk marketplace. *XRDS, 17*(2), 16-21. doi:10.1145/1869086.1869094
- Ipeirotis, P. G. (2010b). Demographics of Mechanical Turk. Available at SSRN: <https://ssrn.com/abstract=1585030>. NYU Working Paper No. ;CEDER-10-01.

- Issaka, R. B., Avila, P., Whitaker, E., Bent, S., & Somsouk, M. (2019). Population health interventions to improve colorectal cancer screening by fecal immunochemical tests: A systematic review. *Prev Med, 118*, 113-121. doi:10.1016/j.yjmed.2018.10.021
- Johanson, L. S. (2017). Caring for Patients of the Millennial Generation: Considerations for Nurses. *Nurs Forum, 52*(3), 207-210. doi:10.1111/nuf.12190
- Johnson, C. M., Wei, C., Ensor, J. E., Smolenski, D. J., Amos, C. I., Levin, B., & Berry, D. A. (2013). Meta-analyses of colorectal cancer risk factors. *Cancer Causes & Control, 24*(6), 1207-1222. doi:10.1007/s10552-013-0201-5
- Jones, R. M., Devers, K. J., Kuzel, A. J., & Woolf, S. H. (2010). Patient-Reported Barriers to Colorectal Cancer Screening: A Mixed-Methods Analysis. *American journal of preventive medicine, 38*(5), 508-516. doi:10.1016/j.amepre.2010.01.021
- Jones, R. M., Vernon, S. W., & Woolf, S. H. (2010). Is discussion of colorectal cancer screening options associated with heightened patient confusion? *Cancer epidemiology, biomarkers & prevention : a publication of the American Association for Cancer Research, cosponsored by the American Society of Preventive Oncology, 19*(11), 2821-2825. doi:10.1158/1055-9965.EPI-10-0695
- Kiechle, E. S., Bailey, S. C., Hedlund, L. A., Viera, A. J., & Sheridan, S. L. (2015). Different Measures, Different Outcomes? A Systematic Review of Performance-Based versus Self-Reported Measures of Health Literacy and Numeracy. *Journal of General Internal Medicine, 30*(10), 1538-1546. doi:10.1007/s11606-015-3288-4
- King-Marshall, E. C., Mueller, N., Dailey, A., Barnett, T. E., George, T. J., Jr., Sultan, S., & Curbow, B. (2015). "It is just another test they want to do": Patient and caregiver understanding of the colonoscopy procedure. *Patient Educ Couns.* doi:10.1016/j.pec.2015.10.021
- King-Marshall, E. C., Mueller, N., Dailey, A., Barnett, T. E., George, T. J., Jr., Sultan, S., & Curbow, B. (2016). "It is just another test they want to do": Patient and caregiver understanding of the colonoscopy procedure. *Patient Educ Couns, 99*(4), 651-658. doi:10.1016/j.pec.2015.10.021
- Klabunde, C., Vernon, S., Nadel, M., Breen, N., Seeff, L., & Brown, M. (2005). Barriers to Colorectal Cancer Screening: A Comparison of Reports From Primary Care Physicians and Average-Risk Adults. *Med Care, 43*(9), 939-944.
- Krieger, J. L., Parrott, R. L., & Nussbaum, J. F. (2011). Metaphor use and health literacy: a pilot study of strategies to explain randomization in cancer clinical trials. *J Health Commun, 16*(1), 3-16. doi:10.1080/10810730.2010.529494
- Lambert, M., Luke, J., Downey, B., Crengle, S., Kelaher, M., Reid, S., & Smylie, J. (2014). Health literacy: health professionals' understandings and their perceptions of barriers that Indigenous patients encounter. *BMC Health Services Research, 14*, 614. doi:10.1186/s12913-014-0614-1
- Lansdorp-Vogelaar, I., Knudsen, A., & Brenner, H. (2010). Cost-effectiveness of colorectal cancer screening – an overview. *Best practice & research. Clinical gastroenterology, 24*(4), 439-449. doi:10.1016/j.bpg.2010.04.004
- Lee, J. K., Liles, E. G., Bent, S., Levin, T. R., & Corley, D. A. (2014). Accuracy of fecal immunochemical tests for colorectal cancer: systematic review and meta-analysis. *Annals of internal medicine, 160*(3), 171-171. doi:10.7326/M13-1484
- Leggett, B. A., & Hewett, D. G. (2015). Colorectal cancer screening. *Internal Medicine Journal, 45*(1), 6-15. doi:10.1111/imj.12636
- Levin, B., Lieberman, D. A., McFarland, B., Smith, R. A., Brooks, D., Andrews, K. S., . . . Winawer, S. J. (2008). Screening and Surveillance for the Early Detection of Colorectal Cancer and Adenomatous Polyps, 2008: A Joint Guideline from the American Cancer Society, the US Multi-Society Task Force on Colorectal Cancer, and the American College of Radiology*†. *CA: A Cancer Journal for Clinicians, 58*(3), 130-160. doi:10.3322/CA.2007.0018

- Lipkus, I. M., & Peters, E. (2009). Understanding the Role of Numeracy in Health: Proposed Theoretical Framework and Practical Insights. *Health Education & Behavior, 36*(6), 1065-1081. doi:10.1177/1090198109341533
- Makoul, G., Cameron, K. A., Baker, D. W., Francis, L., Scholtens, D., & Wolf, M. S. (2009). A multimedia patient education program on colorectal cancer screening increases knowledge and willingness to consider screening among Hispanic/Latino patients. *Patient Educ Couns, 76*(2), 220-226. doi:10.1016/j.pec.2009.01.006
- Marchand, L. L. (1999). Combined influence of genetic and dietary factors on colorectal cancer incidence in Japanese Americans. *J Natl Cancer Inst Monogr*(26), 101-105.
- Mason, W., & Suri, S. (2012). Conducting behavioral research on Amazon's Mechanical Turk. *Behavior Research Methods, 44*(1), 1-23. doi:10.3758/s13428-011-0124-6
- May, F. P., Whitman, C. B., Varlyguina, K., Bromley, E. G., & Spiegel, B. M. (2016). Addressing Low Colorectal Cancer Screening in African Americans: Using Focus Groups to Inform the Development of Effective Interventions. *J Cancer Educ, 31*(3), 567-574. doi:10.1007/s13187-015-0842-z
- Miller, T. A. (2016). Health literacy and adherence to medical treatment in chronic and acute illness: A meta-analysis. *Patient Education and Counseling, 99*(7), 1079-1086. doi:<http://dx.doi.org/10.1016/j.pec.2016.01.020>
- MoneyPantry. (2017). 10 Amazon Turk Tips. Retrieved from <http://moneypantry.com/amazon-mechanical-turk-tips/>
- Mousavinezhad, M., Majdzadeh, R., Akbari Sari, A., Delavari, A., & Mohtasham, F. (2016). The effectiveness of FOBT vs. FIT: A meta-analysis on colorectal cancer screening test. *Medical journal of the Islamic Republic of Iran, 30*, 366-366.
- Mueller NM, K.-M. E., Hyams T, Christie J, Chun J, Curbow BC. (2017). "You wanna avoid it, but they make it so pleasant": Patient Experience of the Colonoscopy Procedure". Paper presented at the American Public Health Association, Atlanta, GA.
- Muir, K. W., Santiago-Turla, C., Stinnett, S. S., Herndon, L. W., Allingham, R. R., Challa, P., & Lee, P. P. (2006). Health Literacy and Adherence to Glaucoma Therapy. *American Journal of Ophthalmology, 142*(2), 223-226.e222. doi:<http://dx.doi.org/10.1016/j.ajo.2006.03.018>
- Murphy, D. A., Lam, P., Naar-King, S., Robert Harris, D., Parsons, J. T., & Muenz, L. R. (2010). Health literacy and antiretroviral adherence among HIV-infected adolescents. *Patient Education and Counseling, 79*(1), 25-29. doi:<http://dx.doi.org/10.1016/j.pec.2009.07.014>
- Nguyen, J., Moorhouse, M., Curbow, B., Christie, J., Walsh-Childers, K., & Islam, S. (2016). Construct Validity of the eHealth Literacy Scale (eHEALS) Among Two Adult Populations: A Rasch Analysis. *JMIR Public Health Surveill, 2*(1), e24. doi:10.2196/publichealth.4967
- Ntiri, D. W., & Stewart, M. (2009). Transformative Learning Intervention: Effect on Functional Health Literacy and Diabetes Knowledge in Older African Americans. *Gerontology & Geriatrics Education, 30*(2), 100-113. doi:10.1080/02701960902911265
- Nutbeam, D. (2000). Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the 21st century. *Health Promotion International, 15*(3), 259-267. doi:10.1093/heapro/15.3.259
- O'Keefe, S. J., Li, J. V., Lahti, L., Ou, J., Carbonero, F., Mohammed, K., . . . Zoetendal, E. G. (2015). Fat, fibre and cancer risk in African Americans and rural Africans. *Nat Commun, 6*, 6342. doi:10.1038/ncomms7342
- Parker, R. M., Baker, D. W., Williams, M. V., & Nurss, J. R. (1995). The test of functional health literacy in adults. *Journal of General Internal Medicine, 10*(10), 537-541. doi:10.1007/BF02640361
- Percheski, C., & Hargittai, E. (2011). Health information-seeking in the digital age. *J Am Coll Health, 59*(5), 379-386. doi:10.1080/07448481.2010.513406

- Peterson, D. (2015). All That Is Solid: Bench-Building at the Frontiers of Two Experimental Sciences. *American Sociological Review*, 80(6), 1201-1225.
- Peterson, N. B., Dwyer, K. A., Mulvaney, S. A., Dietrich, M. S., & Rothman, R. L. (2007). The influence of health literacy on colorectal cancer screening knowledge, beliefs and behavior. *J Natl Med Assoc*, 99(10), 1105-1112.
- Pew Research Center. (2018). Generations and Age.
- Piper, L. E. (2012). Generation Y in healthcare: leading millennials in an era of reform. *Front Health Serv Manage*, 29(1), 16-28.
- Pittman, M., & Sheehan, K. (2016). Amazon's Mechanical Turk a Digital Sweatshop? Transparency and Accountability in Crowdsourced Online Research. *Journal of Media Ethics*, 31(4), 260-262. doi:10.1080/23736992.2016.1228811
- Pleasant, A. (2014). Advancing Health Literacy Measurement: A Pathway to Better Health and Health System Performance. *Journal of Health Communication*, 19(12), 1481-1496. doi:10.1080/10810730.2014.954083
- Rabin, R. C. (2017). What young people need to know about colon cancer. *New York Times*.
- Rat, C., Latour, C., Rousseau, R., Gaultier, A., Pogu, C., Edwards, A., & Nguyen, J. M. (2018). Interventions to increase uptake of faecal tests for colorectal cancer screening: a systematic review. *Eur J Cancer Prev*, 27(3), 227-236. doi:10.1097/cej.0000000000000344
- Rech Wachelke, J. F., Vizeu Camargo, B., Lincoln Bezerra Lins, S., & Vieira de Lima Nunes, A. (2011). Data collection in Internet environment in social representations studies. *Avances en Psicologia Latinoamericana*, 29(1), 11-18.
- Redaelli, A., Cranor, C. W., Okano, G. J., & Reese, P. R. (2003). Screening, prevention and socioeconomic costs associated with the treatment of colorectal cancer. *Pharmacoeconomics*, 21(17), 1213-1238.
- Reyna, V. F. (2008). A Theory of Medical Decision Making and Health: Fuzzy Trace Theory. *Medical decision making : an international journal of the Society for Medical Decision Making*, 28(6), 850-865. doi:10.1177/0272989X08327066
- Reyna, V. F. (2012). A new intuitionism: Meaning, memory, and development in Fuzzy-Trace Theory. *Judgement and Decision Making*, 7(3), 332-359.
- Reyna, V. F., & Brainerd, C. J. (1995). Fuzzy-trace theory: An interim synthesis. *Learning and Individual Differences*, 7(1), 1-75. doi:[http://dx.doi.org/10.1016/1041-6080\(95\)90031-4](http://dx.doi.org/10.1016/1041-6080(95)90031-4)
- Reyna, V. F., Nelson, W. L., Han, P. K., & Dieckmann, N. F. (2009). How numeracy influences risk comprehension and medical decision making. *Psychol Bull*, 135(6), 943-973. doi:10.1037/a0017327
- Rothman, R. L., Montori, V. M., Cherrington, A., & Pignone, M. P. (2008). Perspective: The Role of Numeracy in Health Care. *Journal of Health Communication*, 13(6), 583-595. doi:10.1080/10810730802281791
- Rudd, R., AT, M., & D, N. (2012). Health Literacy and Definitions of Terms. In *Health Literacy in Context: International Perspectives*. Canada: Nova Science.
- Rudd, R. E. (2013). Needed action in health literacy. *J Health Psychol*, 18(8), 1004-1010. doi:10.1177/1359105312470128
- Rust, C., & Davis, C. (2011). Health Literacy and Medication Adherence in Underserved African-American Breast Cancer Survivors: A Qualitative Study. *Social Work in Health Care*, 50(9), 739-761. doi:10.1080/00981389.2011.585703
- Sag, A. A., Selcukbiricik, F., & Mandel, N. M. (2016). Evidence-based medical oncology and interventional radiology paradigms for liver-dominant colorectal cancer metastases. *World J Gastroenterol*, 22(11), 3127-3149. doi:10.3748/wjg.v22.i11.3127

- Sanguinetti, J. M., Lotero Polesel, J. C., Iriarte, S. M., Ledesma, C., Canseco Fuentes, S. E., & Caro, L. E. (2015). Informed consent in colonoscopy: A comparative analysis of 2 modes. *Revista de Gastroenterología de México (English Edition)*, *80*(2), 144-149. doi:<https://doi.org/10.1016/j.rgmxen.2015.03.004>
- Sarfaty, M., & Wender, R. (2007). How to increase colorectal cancer screening rates in practice. *CA Cancer J Clin*, *57*(6), 354-366. doi:10.3322/ca.57.6.354
- Sbaffi, L., & Rowley, J. (2017). Trust and Credibility in Web-Based Health Information: A Review and Agenda for Future Research. *J Med Internet Res*, *19*(6), e218. doi:10.2196/jmir.7579
- Schnitzler, L., Smith, S. K., Shepherd, H. L., Shaw, J., Dong, S., Carpenter, D. M., . . . Dhillon, H. M. (2017). Communication during radiation therapy education sessions: The role of medical jargon and emotional support in clarifying patient confusion. *Patient Education and Counseling*, *100*(1), 112-120. doi:<http://dx.doi.org/10.1016/j.pec.2016.08.006>
- Schwartz, P. H., Edenberg, E., Barrett, P. R., Perkins, S. M., Meslin, E. M., & Imperiale, T. F. (2013). Patient understanding of benefits, risks, and alternatives to screening colonoscopy. *Fam Med*, *45*(2), 83-89.
- Semuels, A. (2018). The Internet Is Enabling a New Kind of Poorly Paid Hell. *The Atlantic*.
- Seurer, A. C., & Vogt, H. B. (2013). Low health literacy: a barrier to effective patient care. *S D Med*, *66*(2), 51, 53-57.
- Siegel, R., DeSantis, C., & Jemal, A. (2014). Colorectal cancer statistics, 2014. *CA: A Cancer Journal for Clinicians*, *64*(2), 104-117. doi:10.3322/caac.21220
- Siegel, R. L., Miller, K. D., Fedewa, S. A., Ahnen, D. J., Meester, R. G. S., Barzi, A., & Jemal, A. (2017). Colorectal cancer statistics, 2017. *CA Cancer J Clin*, *67*(3), 177-193. doi:10.3322/caac.21395
- Siegel, R. L., Miller, K. D., Fedewa, S. A., Ahnen, D. J., Meester, R. G. S., Barzi, A., & Jemal, A. (2017). Colorectal cancer statistics, 2017. *CA: A Cancer Journal for Clinicians*, *67*(3), 177-193. doi:10.3322/caac.21395
- Smith, S. G., Raine, R., Obichere, A., Wolf, M. S., Wardle, J., & von Wagner, C. (2015). The effect of a supplementary ('gist-based') information leaflet on colorectal cancer knowledge and screening intention: a randomized controlled trial. *Journal of Behavioral Medicine*, *38*(2), 261-272. doi:10.1007/s10865-014-9596-z
- Smith, S. G., Vart, G., Wolf, M. S., Obichere, A., Baker, H. J., Raine, R., . . . von Wagner, C. (2015). How do people interpret information about colorectal cancer screening: observations from a think-aloud study. *Health Expect*, *18*(5), 703-714. doi:10.1111/hex.12117
- Smith, S. G., Wolf, M. S., Obichere, A., Raine, R., Wardle, J., & von Wagner, C. (2013). The development and testing of a brief ('gist-based') supplementary colorectal cancer screening information leaflet(). *Patient Education and Counseling*, *93*(3), 619-625. doi:10.1016/j.pec.2013.08.013
- Subramanian, S., Tangka, F. K., Hoover, S., Nadel, M., Smith, R., Atkin, W., & Patnick, J. (2016). Recommendations From the International Colorectal Cancer Screening Network on the Evaluation of the Cost of Screening Programs. *J Public Health Manag Pract*, *22*(5), 461-465. doi:10.1097/phh.0000000000000386
- Taggarshe, D., Rehil, N., Sharma, S., Flynn, J. C., & Damadi, A. (2013). Colorectal cancer: are the "young" being overlooked? *Am J Surg*, *205*(3), 312-316; discussion 316. doi:10.1016/j.amjsurg.2012.10.016
- Weiss, B. D., Hart, G., McGee, D. L., & D'Estelle, S. (1992). Health status of illiterate adults: relation between literacy and health status among persons with low literacy skills. *J Am Board Fam Pract*, *5*(3), 257-264.
- Whitley, J., Smith, J. D., & Vaillancourt, T. (2013). Promoting Mental Health Literacy Among Educators. *Canadian Journal of School Psychology*, *28*(1), 56-70. doi:10.1177/0829573512468852

- Williams, M. V., Davis, T., Parker, R. M., & Weiss, B. D. (2002). The role of health literacy in patient-physician communication. *Fam Med*, *34*(5), 383-389.
- Williams, R., White, P., Nieto, J., Vieira, D., Francois, F., & Hamilton, F. (2016). Colorectal Cancer in African Americans: An Update: Prepared by the Committee on Minority Affairs and Cultural Diversity, American College of Gastroenterology. *Clinical and Translational Gastroenterology*, *7*(7), e185. doi:10.1038/ctg.2016.36
- Wolf, A., Fonham, E., Church, T. R., Flowers, C. R., Guerra, C. E., LaMonte, S. J., . . . Smith, R. A. (2018). Colorectal cancer screening for average-risk adults: 2018 guideline update from the American Cancer Society. *CA: A Cancer Journal for Clinicians*, *68*(4), 250-281. doi:doi:10.3322/caac.21457
- Wolf, M. S., Baker, D. W., & Makoul, G. (2007). Physician–Patient Communication about Colorectal Cancer Screening. *Journal of General Internal Medicine*, *22*(11), 1493-1499. doi:10.1007/s11606-007-0289-y
- Wolf, M. S., Curtis, L. M., Wilson, E. A. H., Reville, W., Waite, K. R., Smith, S. G., . . . Baker, D. W. (2012). Literacy, Cognitive Function, and Health: Results of the LitCog Study. *Journal of General Internal Medicine*, *27*(10), 1300-1307. doi:10.1007/s11606-012-2079-4
- Yardley, C., Glover, C., & Allen-Mersh, T. G. (2000). Demographic factors associated with knowledge of colorectal cancer symptoms in a UK population-based survey. *Annals of the Royal College of Surgeons of England*, *82*(3), 205-209.
- Yee, L. M., & Simon, M. A. (2014). The Role of Health Literacy and Numeracy in Contraceptive Decision-Making for Urban Chicago Women. *Journal of Community Health*, *39*(2), 394-399. doi:10.1007/s10900-013-9777-7
- Zikmund-Fisher, B. J., Smith, D. M., Ubel, P. A., & Fagerlin, A. (2007). Validation of the Subjective Numeracy Scale: effects of low numeracy on comprehension of risk communications and utility elicitation. *Med Decis Making*, *27*(5), 663-671. doi:10.1177/0272989x07303824
- Zolnierok, K. B., & Dimatteo, M. R. (2009). Physician communication and patient adherence to treatment: a meta-analysis. *Med Care*, *47*(8), 826-834. doi:10.1097/MLR.0b013e31819a5acc