EXAMINING UNCERTAINTY MANAGEMENT AND INFORMATION BEHAVIOR IN THE CONTEXT OF RECRUITMENT FOR CLINICAL RESEARCH

By

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To Andreui, mom, and dad
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<td>M</td>
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<td>National Institutes of Health</td>
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Chair: Debbie Treise
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Major: Mass Communication

Participation of volunteers in clinical research is crucial for the discovery of new treatments, but the decision to participate in a clinical study is associated with a number of uncertainties related to clinical study randomization or evaluation of the possible outcomes of participation in clinical research. Uncertainty management theory (UMT; Brashers, 2001) identifies uncertainty appraisal and information behavior as mechanisms of uncertainty management. Extending the propositions of UMT to explain behavioral intention, this dissertation evaluated an explanatory model that assessed the causal pathways to informed decision-making under uncertainty in the context of recruitment for clinical research.

Primary study hypotheses were tested using an online experiment (N = 340) and identified information-seeking self-efficacy and trust in medical researchers as significant covariates contributing to decisions to participate in clinical research. The final explanatory model showed a significant indirect effect of decisional uncertainty on behavioral intention, mediated by uncertainty appraisal and information behavior, $F(4, 335) = 21.56$, $R^2 = .20$, $p < .01$. Specifically, a serial mediation model showed that
decisional uncertainty mediated by threat appraisal, challenge appraisal, and information seeking results in decreased behavioral intention to participate in a clinical study. Conversely, the pathway mediated by threat appraisal and information avoidance was shown to lead to an increase in behavioral intention to participate in clinical research.

Although uncertainty had an overall negative effect on participation in clinical research, the path from higher uncertainty to lower behavioral intention is not direct, and uncertainty itself was not found to be a direct predictor of participation or non-participation in clinical research. Extending the theory of uncertainty management (Brashers, 2001), this dissertation provided preliminary evidence for a general framework linking uncertainty and behavior. In addition, this finding suggests that knowledge translation and dissemination efforts should account for the prospective participants’ uncertainty management needs rather than focusing primarily on minimizing uncertainty contained in study description and recruitment messages.
CHAPTER 1
INTRODUCTION

“Medical progress is based on research that ultimately must include studies involving human subjects.”
-- Article #5, the Declaration of Helsinki (World Medical Association, 2013, p. 2191)

Uncertainty and Participation in Clinical Research

The lack of participation in medical research has been recognized as one of the primary barriers to the successful translation of basic science discoveries into human studies and further translation of clinical science evidence into health practice and decision-making (Sung et al., 2003). The ability to recruit clinical research participants is one of the key challenges associated with developing and putting a drug or device on the market. Recruitment for participation in clinical research remains one of the major challenges in scientific progress toward effective medical treatments (Bevan, Chee, McGhee, & McInnes, 1993; Biedrzycki, 2010).

As advocated by the quote in the beginning of this chapter, participation of volunteers in clinical research is crucial for the discovery of new treatments. This notion is supported by the majority of U.S. adults (Comis, Miller, Aldigé, Krebs, & Stoval, 2003). Yet only about 10% of U.S. health consumers have participated in at least one clinical study (Health Information National Trends Survey (HINTS), 2012). For cancer clinical studies, this number fluctuates around 2-4 percent and is even lower among African American and Hispanic individuals (Murthy, Krumholz, & Gross, 2004). In addition, regardless of race, health consumers who are recruited to participate in cancer clinical trials are unsatisfied with the information about clinical research that is available to them (Madsen et al., 2002), which signals the need for knowledge translation and
dissemination research to inform the scholarship and practice of recruitment and informed consent in the context of clinical research.

Low participation in clinical research can originate from research design, structural barriers, or cognitive and psychological perceptual factors. Study design barriers are enrollment limitations imposed by the criteria set by the study protocol. Clinical inclusion criteria established by a study protocol are the most explicit structural barriers that exist in clinical research recruitment. These criteria are essential but can create systematic exclusion practices. For example, one meta-analysis found that women are excluded from trials more often than men (Murthy et al., 2004). In addition to clinical disqualifiers, patients from lower socio-economic groups face possible structural barriers including the cost of additional standard-of-care testing that may not be fully covered by insurance (Comis et al., 2003). Lack of insurance coverage for studies that involve a standard-of-care treatment comparison is another structural barrier. Potential participants who are uninsured or underinsured could face a barrier related to standard-of-care costs included as comparative study procedures for which there is no reimbursement (Comis et al., 2003). Furthermore, time commitments and travel costs associated with study participation can preclude participation of a number of sociodemographic groups.

In addition to the design and structural barriers, a number of information dissemination and cognitive processing barriers can contribute to low clinical study participation. Ineffective dissemination of information leads to a lack of awareness about available clinical studies and subsequent challenges in clinical research enrollment (Advani et al., 2003). Despite efforts to make information about clinical research
available to prospective participants (Friedman et al., 2014), patient-centered recruitment messages that communicate about clinical research, its importance, and study-related specifics are still inadequate in providing sufficient knowledge (Kim, Tanner, Friedman, Foster, & Bergeron, 2015). Cognitive and psychological barriers that stem from the lack of understanding of clinical research further contribute to low participation in clinical research. These factors include a lack of knowledge about diseases and conditions, poor understanding of the process of clinical research, misunderstanding of randomization, and general distrust in medical researchers (Biedrzycki, 2010; Comis et al., 2003). A number of studies have documented the role of cognitive and psychological uncertainties that contribute to low participation in clinical research. These uncertainties include a lack of knowledge about clinical research, fear, distrust, and perceived risks. A national survey showed that at least 40% of Americans do not understand the clinical research process (Comis et al., 2003).

Low levels of knowledge about the process of clinical research (e.g., randomization, subject protection) can impede participation (Jones et al., 2007). Specifically, as earlier research showed, if prospective participants perceive themselves to be more knowledgeable about clinical research, they are more likely to express an intention to participate in a study (Jones et al., 2007). Another barrier to participation in clinical research is the lack of public trust in medical research in general and medical researchers in particular. The skepticism and distrust in medical research stems from the historical abuse of vulnerable study participants (Fisher & Kalbaugh, 2011; D. J. Rothman, 1982) and is fueled by news reports about the unethical behavior of some clinical researchers (Cohen, 2003).
As discussed previously, significant barriers for participant recruitment are related to ineffective communication. These barriers are associated with the challenges of translating and disseminating information about the clinical trial process, promoting the role of clinical research in the development of new medical treatments, and supporting prospective participants in their decisions to accept or reject invitations to participate in clinical research studies. However, these barriers largely fall within the deficit paradigm of knowledge dissemination that assumes that challenges in individual health decisions stem from a lack of knowledge (Bubela et al., 2009). An alternative view of knowledge dissemination and management is advocated by the proponents of the translational communication approach (Frey, 2009; Krieger & Gallois, in press; Parrott, 2008). This emerging paradigm in communication research suggests that information behaviors exhibited by information consumers are intentional and serve as indicators of knowledge management and meaning making in the process of knowledge translation for decision-making. Guided by this approach, this study seeks to advance communication theory and provide empirical knowledge in the area of health communication and uncertainty management. Specifically, the appraisal of uncertainty and information behavior as uncertainty management mechanisms are evaluated in the context of recruitment for participation in clinical research. The next section provides a brief overview of the challenges and opportunities faced by researchers engaged in interdisciplinary clinical translational science and discusses the role of communication science as a translational science discipline.

**Translational Communication Research**

Translation of medical knowledge into practice is supposed to be a culmination of the scientific process, but it is not without challenges. On the one hand, the translation
of clinical knowledge is challenged by the fact that the outcomes of clinical research and subsequent health recommendations can carry substantial uncertainty, which are unlikely to be welcomed by the general public (Han, Moser, & Klein, 2006; Pollack, 2003). At the same time, direct public participation in research is essential for the successful progression of medical knowledge (World Medical Association, 2013). Such participation may come in the form of public debate, active engagement in community initiatives, or, most directly, through participation in randomized and observational clinical research studies.

Definitions of knowledge translation vary from narrowly focusing on the synthesis of research findings through systematic reviews (Grimshaw, Eccles, Lavis, Hill, & Squires, 2012) to including comprehensive processes of putting knowledge into action that involve problem identification, knowledge tailoring, knowledge use implementation, and evaluation (Straus, Tetroe, & Graham, 2009). Communication plays a key role in the process of knowledge translation, and translational communication research aims to produce evidence for successful adoption of knowledge for practical application and broad public consumption. Communication research supports dissemination and implementation activities by identifying opportunities and mechanisms for public engagement and participating in support for the process of scientific discovery. The core indicator for the success of this translational process is not the simple application of previously obtained knowledge but the implementation of findings that contribute to positive changes in the quality of human lives and well-being (Parrott, 2008).

Translational communication research is an emerging field, and the process and operationalization of the practice of translational communication research are debated
by communication scholars. Some argue that by involving in translational research communication scholars have made interdisciplinary contributions and have moved communication as a discipline into prominent roles in policy, including positions that afford opportunities to participate in and have input into far-reaching decisions (Parrott, 2008). Others have a more focused view of translational communication, viewing research as a pathway to serviceable practices (Petronio, 2007). The main argument for the role of translational communication research, though, is that there is limited relevance and use of translational scholarship when it seeks application through research in a post hoc way. Rather, communication scholarship can make a stronger contribution by being applied to specific situations affected by communication (Frey, 2009) when health communication scholars engage in interdisciplinary translational research in collaboration with colleagues from other disciplines (Parrott, 2008). The main goal of translational communication research is, therefore, to use resources available to communication scholars to apply health communication research and theory to improving health outcomes in society (Kreps, 2012), addressing applied, real-world problems and promoting desired behavioral outcomes.

Translational research is part of the general scientific discovery process that comes at a stage where fundamental discoveries are translated, disseminated, and introduced into practice. Most commonly, scholarly activities lead to the generation of scientific evidence that can be classified into three categories (Rabin & Brownson, 2012). Type 1 evidence looks at the causes and factors that contribute to a specific problem and determines what actions are necessary. Type 2 evidence evaluates efficacy and effectiveness of specific interventions to suggest practice changes with
best-available evidence. Finally, Type 3 evidence seeks information to support successful uptake of the interventions while providing guidance on how something should be done (Rabin & Brownson, 2012). This type of evidence is situational and most scarce. Arguably, it also is an area where translational communication scholars could make the most impact by translating the evidence that most readily points to viable interventions (Parrott, 2008), e.g., to support knowledge acquisition, information processing, and decision making among prospective clinical research participants. An overview of extant research on information processing will be presented next, and the specifics of information processing in response to uncertainty will be further discussed in the Literature Review section.

A communication model that provides a theoretical framework for the stages of information processing was proposed by McGuire (1968). The model includes six stages and starts with the initial presentation of information when recipients are exposed to a message. The second step occurs when a recipient pays attention to the message. The third step is comprehension that is achieved when the recipient understands the message. Step four involves yielding when a recipient agrees with the message and forms a positive attitude toward the promoted behavior. Step five is retention, when a recipient remembers the message and internalizes the attitude toward the promoted behavior. The final step is the behavior that manifests in the recipient acting on the advocated message.

McGuire’s model of information processing provides a useful approach to understanding the stages in a communication process. This framework has been applied to a number of topics, including communication about clinical trials. One
exploratory study used it to assess exposure and attention to messages that employ metaphors to explain randomization (Krieger, Parrott, & Nussbaum, 2010). The study found that attention played a mediating role in explaining the effects of different randomization messages on intentions to participate in clinical trials and suggested that exposure to information about the study background should be included as an explicit step in the communication efforts related to the promotion of and recruitment into clinical studies.

The information-processing model was developed for the examination and explanation of discrete behaviors. However, this focus has limited ability to capture the full spectrum of communication that surrounds participation in clinical research. The clinical research communication process is a useful heuristic for thinking about the communication related to participation in clinical research because each stage has its own challenges. Ideally, communication across the clinical research process should be supported by appropriate messages that deliver relevant and sufficient information to support individuals’ full understanding of the health management options and choices available to them—an essential component of the U. S. national goals for health communication and health information technology (Office of Disease Prevention and Health Promotion, 2015). Extending the application of the information-processing model, the clinical research communication process can be conceptualized to have its own specific six stages, namely, awareness about clinical research, attention to recruitment messages, comprehension of study specifics, informed consent, participation and successful retention, and advocacy (Figure 1-1). A brief overview
below provides examples of communication strategies that could be used at the stages of the clinical trial communication process.

![Diagram of the clinical research communication process](image)

**Figure 1-1. A model of the clinical research communication process**

In raising awareness about clinical research, health communicators have a choice of strategies. Health information is ubiquitous, but its uptake depends on the ability of information sources to narrowcast their messages and provide timely and relevant information according to the needs of the audience (Rimal & Adkins, 2003). On the part of receivers, the ability to find relevant information is a core health management skill that is challenged by the currently oversaturated information environment (Centers for Disease Control and Prevention, 2015). As health information consumers become selective in their exposure to health information (Knobloch-Westerwick & Sarge, 2015), audience segmentation and targeted delivery of recruitment messages can lead to an increase in awareness about clinical research.

Audience segmentation refers to a process of dividing potential message consumers into groups based on some criteria relevant to the specific objectives of a
particular health communication intervention (Rimal & Adkins, 2003). The goal of audience segmentation is to identify different groups of information consumers who share some common key characteristics that may shape their engagement with different messages. Practically, audience segmentation aims to identify the fewest number of groups that are homogenous enough to have similar reactions to health messages. For example, messages designed to recruit participants to a clinical study might segment the audience into groups of people who have been approached to participate in research studies before and those who have not. Similarly, a campaign that aims to increase knowledge about a field of medical research in general, for example, about cancer-related research, might segment information consumers according to whether they have family members affected by cancer, whether they belong to a group at a higher risk of developing cancer, and so on.

Targeting is defined by its ability to reach specific population subgroups. The most commonly accepted view equates audience segmentation and targeting (Kreuter & Wray, 2003), while an alternative view differentiates targeting as a strategy focused on channel-selection (Rimal & Adkins, 2003). For example, in addition to psychological, social, or demographic characteristics, audiences may also differ in their preference for different information channels. Recruiting older adults through newspaper advertisements may be more effective than targeting them on social media, but Twitter might be a preferred channel for reaching young adults. Therefore, if audience segmentation informs the choice of audience groups, targeting informs the choice of a message delivery channel.
The delivery of tailored information can be more effective in reaching targeted audiences and increasing attention to information about clinical research. Tailoring is defined as a process of customization of a message based on some key individual characteristics of audience members (Kreuter & Wray, 2003). Through the use of computer-mediated communication, messages can be tailored to include a combination of elements that are most relevant in persuading a message receiver to undertake a certain behavior. For example, a message promoting cancer screening may include information about specific risks and appeal to individual beliefs based on personal information obtained prior to message dissemination. In the context of health care provision, health consumers may receive a screening test reminder through their electronic medical chart that would address them by their name, provide an estimate of their cancer risks based on their age, gender, and ethnicity, and contain a persuasive cue based on this person’s medical history.

Message format could also be considered in the process of message design as a means to gain audience attention. The preferred modality of a message and richness of the information delivered by the message might depend on the channel through which the message will be delivered. The information richness theory (Trevino, Lengel, & Daft, 1987) describes interpersonal communication messages as the richest in their potential to convey information. Video messages provide fewer opportunities for active engagement with the message but are still characterized by their ability to carry and deliver rich content. Messages with still images are less rich, and text-only messages are the most limited. However, the richest message is not always the most effective. For example, social media information consumption is characterized by preference for “bite-
size” information that can be consumed quickly. Therefore, in the social media context, a video may be less effective in delivering information about cancer research than a text message with an image (Strekalova & Krieger, 2015).

Moving beyond attention, comprehension of information can be supported by the use of culturally appropriate language and linguistic message strategies. Language considerations focus on the choice of words as several fruitful lines of research have identified the effect of linguistics on communication outcomes. One linguistic strategy—the use of metaphors to explain complex, unfamiliar concepts—can aid in increasing message effectiveness. Metaphors are cognitive aids that allow individuals to connect new information with more familiar experiences to ascribe meaning (Lakoff & Johnson, 1980). For example, in communication about clinical trial participation, randomization has been identified as one of the core communication challenges. For prospective participants, randomization, in most cases, involves an equal chance of being assigned to a treatment or control group. This equal chance creates the highest level of uncertainty, which is frequently explained as a flip of a coin. While this metaphor is easy to understand, research that examined communication about the coin-flip metaphor showed that it could create a negative perception about the process of randomization equating it to something that is not worth serious consideration or something akin to a gamble (Krieger, 2013). Alternatively, explanation of randomization as a chance of having a baby of a particular sex would be perceived as more serious yet positive imagery (Krieger, 2013).

To achieve informed consent, clinical study teams can use communication strategies that promote active participation of prospective study participants in the
process of information exchange and question asking. A number of studies have evaluated the participation of patients in active communication during medical office visits (Cegala, McClure, Marinelli, & Post, 2000; Cegala, Post, & McClure, 2001). These studies showed that patients benefitted from communication interventions that allowed them to think about upcoming office visits. By taking some time in advance to review and prepare questions for medical visits, patients are better prepared to more actively participate in the discussion and decision making related to their health and well-being (Cegala et al., 2001). Although face-to-face communication skill training is prohibitively costly, tailored computer-mediated solutions can create opportunities for tailored interventions that will be accessible and available for large groups of health consumers (Cegala, 2003). Similarly, prospective clinical study participants could benefit from being exposed to brief messages about studies and getting support in looking for information and formulating questions before meeting with research team members for consenting and study enrollment.

In supporting participation and retention of enrolled participants, necessary considerations should be made for the evaluation of the potential communication outcomes. A particular message strategy, framing, can be used to communicate about the value of a decision related to clinical research. Effects of message framing in terms of gains or losses stem from the prospect theory (Kahneman & Tversky, 1979). The theory explains that, in general, people are loss averse and perceive losses as having a bigger effect than gains. For example, a message about the losses that could stem from not participating in a cancer prevention activity is likely to be more persuasive than a message that focuses on the possible benefits of getting regular Pap smears or
colonoscopies (Gallagher & Updegraff, 2011). However, when possible outcomes are not certain, people will prefer sure smaller gains over probable larger gains and will accept larger probabilistic losses compared to sure smaller losses. For example, the theory predicts that people are more persuaded to comply with cancer screening recommendations if they are told that their participation could prevent penalties from insurance companies for being out of compliance than if they are offered a discount for their participation.

In addition to the outcomes of behavior, outcomes of messages should also be assessed and evaluated. Health communication efforts pursue specific outcomes and behaviors, but some messages may lead to unintended consequences. These consequences may include stigma (Smith, 2007), information overload and avoidance (Case, Andrews, Johnson, & Allard, 2005), boomerang effects and psychological reactance (Wolburg, 2006), or dramatization. For example, research on the inclusion of fear appeals in messages is addressed in the extended parallel processing model (Witte & Allen, 2000). Fear can be a potent motivator for protective behavior. The strength of a fear appeal might activate different response mechanisms. A balanced fear appeal should lead to a protective action and persuade the audience to engage in a prescribed behavior. Weak fear appeals might be ineffective and perceived as personally irrelevant. At the same time, strong fear appeals may lead to a defensive response and force an individual to focus on the fear itself rather than on the recommended behavior.

In promoting advocacy, communication strategies could look at the choice of rhetorical composition techniques. Specifically, information can be presented through a narrative that tells the story of a person in a particular health context. Alternatively,
similar information can be presented as a more objective discussion of facts and statistical data related to the same situation. A recruitment message can share a brief quote from a clinical study investigator who is a breast cancer survivor, or it could provide quotes from a number of women who have been affected by breast cancer. Extant research strongly supports the use of narratives as more conducive to the comprehension of new information (Hinyard & Kreuter, 2007).

Health communication and knowledge translation efforts do not happen in isolation, and a number of factors impact message effects. These factors can include self-efficacy and response efficacy, information literacy and communication skills, perceptions of susceptibility for a particular disease or its severity, attitudes toward a particular issue, and strength of those attitudes (Conner, Povey, Sparks, James, & Shepherd, 2003; Thompson, Zanna, & Griffin, 1995). In addition, sociocultural factors can shape perceptions about an uncertain health-related phenomenon and influence information behavior (Bradac, 2001; Brashers, 2001). The lack of knowledge about an unfamiliar object or event may lead to a feeling of uncertainty (Brashers, 2001). For example, a person who knows very little about clinical trials may feel uncertain about the process of clinical research, possible outcomes for participants, or whether volunteer participation in clinical trials in general is good or bad (Comis et al., 2003). Information provision can serve as a mechanism to reduce uncertainty, but it can also increase uncertainty and subsequently affect how recruitment messages promoting participation in clinical research are perceived and processed. Therefore, evaluation and deliberate selection of communication strategies can aid in translating and
delivering appropriate and relevant information to support effective decision-making related to participation in clinical research.

**Role of Current Study**

Despite significant efforts to promote informed decision-making during recruitment for clinical research, prospective research participants can intentionally avoid information related to the topic or procedures associated with a research study (Yang, 2012). Subsequently, the understanding of the pathways that lead to informed intention to participate in clinical research has been named a high research priority supported by several national agencies (e.g., National Institutes of Health, 2013; Patient-Centered Outcomes Research Institute, 2015).

The propositions put forth by uncertainty management theory (UMT) provide a robust theoretical framework for the evaluation of uncertainty and informed decision-making related to clinical study recruitment (Brashers, 2001; Brashers & Hogan, 2013) thus informing knowledge translation and dissemination efforts related to clinical research. UMT posits that information behavior is situational and depends on how uncertainty is appraised and how individuals assess their skills to manage the uncertainty. Subsequently, the appraisal of uncertainty shapes information behaviors exhibited by health consumers as a response to uncertainty.

In the context in which informed decision-making is essential, like participation in clinical research, the understanding of the relationship between uncertainty and information seeking gains increased relevance. UMT propositions focus on antecedent, information behavior factors that are viewed as precursors to decisions; it identifies several core constructs that provide a theoretical framework for exploring and explaining information behaviors under uncertainty. UMT aims to explain behavior under
uncertainty but does not explicitly include decision-making and behavioral intention. Contributing to this line of research, the goal of this study is to extend the propositions developed under UMT to a new conceptual model. Specifically, it seeks to examine the relationships among uncertainty evoked by recruitment messages promoting participation in a clinical study, uncertainty appraisal, and information behavior, and suggest pathways that explain behavioral intention to participate in clinical research.

The proposed explanatory model, which is applicable both for the explanation of the decisions to join a clinical study in response to a recruitment message and the decisions to reject an invitation to participate, aims to assess the role of uncertainty in knowledge translation and to uncover causal pathways to informed decision-making in the context of recruitment for clinical research.

**Study Overview**

Chapter 1 provided a brief overview of the opportunities and challenges of clinical translational research and the contribution of communication as a translational scholarship discipline. Chapter 2 provides a discussion of UMT (Brashers, 2001), the communication theory that evaluates the role of communication in uncertainty management. The main theoretical propositions put forth by the theory are also discussed in the context of recruitment for participation in clinical research. Specifically, the role of situation-specific uncertainty, self-efficacy, and uncertainty appraisal in affecting informed decision-making are discussed in relation to explaining behavioral intentions for participation in a clinical research study. Based on the propositions supplied by the UMT theory and its application to clinical research recruitment, a number of hypotheses are formulated to evaluate the proposed moderated mediation model of informed decision-making during recruitment for clinical research. Chapter 3
presents an approach for testing the model. Chapter 4 presents the results of the tests of the hypotheses and the overall model. Finally, Chapter 5 discusses the results, limitations, and theoretical and practical implications.
CHAPTER 2
LITERATURE REVIEW

Communication and Uncertainty Management

The effect of uncertainty in the process of communication has a rich research tradition that started with a focus on the understanding of uncertainty and ways to reduce it. Subsequent theoretical developments recognized that individuals could seek outcomes other than uncertainty reduction. Consequently, theorizing about uncertainty and communication evolved into a focus on the strategies and processes that come into play in the process of uncertainty management. The next sections provide an overview of the communication scholarship related to uncertainty and the relevant theoretical constructs.

Uncertainty Reduction

Although the world is fundamentally uncertain and unpredictable (Pollack, 2003), accepting this notion is hard. Uncertainty is a complex phenomenon closely related to communication, and prior research that discusses this topic, for the most part, is represented by two competing views of uncertainty. Earlier research on this topic focused on the understanding of uncertainty as an unstable and temporary state. Subsequently, uncertainty communication theories aimed to identify the causes of uncertainty and strategies to reduce it (Berger, 1986; Gudykunst, Yang, & Nishida, 1985).

In the medical sciences, the dominant biomedical paradigm is based on the discovery of knowledge to cure diseases and the identification of symptoms for accurate diagnosis and subsequent treatment. Similarly, one of the prominent communication theories, the uncertainty reduction theory (URT), proposes that humans see uncertainty
as a threat and are motivated to reduce it through communication (Berger & Calabrese, 1975). The uncertainty reduction theory (URT) ascribed an uncertainty reduction role to communication and information seeking (Berger, 1986; Gudykunst & Nishida, 1984).

“Central to the present theory is the assumption that when strangers meet, their primary concern is one of uncertainty reduction or increasing predictability about the behavior of both themselves and others in the interaction” (Berger & Calabrese, 1975, p. 100).

In its general form, the uncertainty reduction theory predicts that if individuals face alternatives for possible behaviors or situations, they will feel a greater sense of uncertainty as the number of those alternatives increases. This view of uncertainty suggests that individuals experiencing uncertainty will seek to reduce it. URT aims to identify causes and predict consequences of uncertainty and does it through identifying seven axioms that yield 21 theorems. Focusing on uncertainty in interpersonal communication, the axioms state that (1) interpersonal situations cause uncertainty, (2) uncertainty is an aversive state that generates stress, (3) in communication between strangers, their primary goal is to reduce uncertainty about each other, (4) communication occurs in stages, (5) communication is the means to reduce uncertainty, (6) the nature of exchanged information changes over time, and (7) people’s behavior can be explained through law-like predictions.

In addition to the comprehensive coverage of social-behavioral constructs, the URT also offers parsimony in explaining the relationship between uncertainty and information behavior. The broad applicability of these two constructs to communication situations led to the theory’s popularity and wide adoption. However, as was pointed out by later research (e.g., Bradac, 2001), the theory oversimplifies people’s reactions to
uncertainty by assuming that people will always seek to reduce uncertainty. It also falls short in accounting for situations in which uncertainty cannot be reduced because existing or acquired knowledge remains incomplete, ambiguous, or probabilistic.

Uncertainty is central to the experience of health and health decision-making. In one paper, Babrow and Kline argue vigorously against the notion that uncertainty reduction is always a logical goal, contending “that the single-minded and unreflective promotion of uncertainty reduction is both limiting and potentially dangerous” (Babrow & Kline, 2000, p. 1805). The possibility of uncertainty reduction may be limited when knowledge is insufficient to resolve the uncertainty, when reducing uncertainty regarding one issue may result in a cascade of consequent uncertainties, or when uncertainty itself is perceived as a source of hope and a shield from unpleasant thoughts. Assessments and experiences of uncertainty are also likely to vary from individual to individual, and actions narrowly aimed at uncertainty reduction may lead to misunderstanding and miscommunication. Uncertainty is a state that, at times, may be sought after (Babrow & Kline, 2000; Brashers et al., 2000) and that warrants management and coping behaviors (Bradac, 2001; Brashers, 2001). Consequently, communicative behaviors are assigned a more complex role that results in uncertainty integration, reappraisal, reduction, or maintenance (Bradac, 2001; Brashers et al., 2000; Ford, Babrow, & Stohl, 1996).

**Uncertainty Management Theory**

The second view of uncertainty describes it as a more complex phenomenon. According to an explication proposed by Brashers (2001), uncertainty is not automatically evaluated as a negative state that should be avoided. Rather, the management of uncertainty is situational and depends on its appraisal. This section
discusses the propositions put forth by the uncertainty management theory (UMT, Brashers, 2001).

UMT (Brashers, 2001) was developed as a critique of and an alternative to the conceptualization of communication as a mechanism for uncertainty reduction that dominated research in the 1980s and 1990s (Berger, 1986; Bradac, 2001; Gudykunst et al., 1985; Mishel, Padilla, Grant, & Sorenson, 1991). UMT is a relatively new theory and was proposed by Brashers based on his own work and the work of other communication scholars (Babrow, 1992; Brashers et al., 1999; Brashers & Babrow, 1996; Ford et al., 1996) as a broader theory of communication and uncertainty management that goes beyond uncertainty reduction (Brashers, 2001). The goal of UMT is to offer specific predictions about communicative behavior in situational contexts affected by uncertainty (Brashers & Babrow, 1996).

The significance of uncertainty as a topic of health communication research is suggested by the observation that assessment of facts and values is central to individual decision-making about health and well-being. The central conceptual role of uncertainty is acknowledged by research focused on uncertainty and illness (Brashers et al., 1999; Mishel et al., 1991), stress and psychological coping (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986; Ford et al., 1996), literacy and information behavior (Basu & Dutta, 2008; Beaudoin & Hong, 2011; Johnson, 1997), and health engagement and activation (Chen et al., 2015; Hibbard & Greene, 2013; Mello, Tan, Armstrong, Schwartz, & Hornik, 2013).

Brashers (2001) defines uncertainty as a state that people perceive and define individually. The vagueness of this definition is somewhat indicative of the scholarly
discussions about the definition of uncertainty. From an ontological standpoint, the conceptualization of uncertainty provokes an ongoing debate that seeks to define what uncertainty is and what it is not. One line of thinking argues that any uncertainty can be reduced to an evaluation of probabilistic outcomes. This view is advocated by the classical work on judgment under uncertainty (Dolan & Kahneman, 2008; Slovic, Peters, Finucane, & MacGregor, 2005) and clinical decision making (Brewer, Chapman, Schwartz, & Bergus, 2007; Reyna, 2008). Explicating the state of being unknown, decision scholarship suggested a differentiation between risk and uncertainty. The former relates to the situation that has a probabilistic outcome with a known probability distribution. For example, the outcome of a randomization into a clinical study is unknown until the randomization takes place, but the probability of outcomes is known to be 50/50 (for a two-arm study). The latter refers to a situation in which the probability of a preferred outcome is unknown. This definition provides delineation for objective decision-making and seeks to maximize possible utility, or final value, of the outcome. However, most human decision-making is subjective. Furthermore, a situation with known probabilities of outcomes could still be uncertain if personal values assigned to these outcomes are unclear. For example, a cancer patient facing a treatment choice decision may be uncertain about the preferred choice.

Another conceptualization of uncertainty accepts a broader interpretation of its nature. This second interpretation defines uncertainty as a state of confusion about the meaning of some information (Brashers, 2001; Folkman & Lazarus, 1980). Specifically, UMT proposes the following broad definition:

Uncertainty exists when details of situations are ambiguous, complex, unpredictable, or probabilistic; when information is unavailable or
inconsistent; and when people feel insecure in their own state of knowledge or the state of knowledge in general (Brashers, 2001, p. 478).

In other words, conceptualizing uncertainty, UMT recognizes that uncertainty may have a number of sources, but ultimately states that uncertainty is situational and perceptual (Brashers, 2001).

Health information consumers may experience uncertainty because they perceive their knowledge about a health issue as insufficient (Brashers, 2001), or because they are uncertain about their evaluation of that issue (Babrow, 2001).

UMT proposes that information behavior is situational and depends on how uncertainty is appraised and how individuals assess their skills for managing the uncertainty. Subsequently, the appraisal of uncertainty shapes information behavior exhibited by health consumers as a response to uncertainty. Once recognized, perceived uncertainty can be managed through communication. In some situations, health consumers may seek to reduce their uncertainty, but they may also maintain it when uncertainty gives them hope. In their study involving those diagnosed with HIV, Brashers and colleagues showed that for chronically ill patients who need to adapt to chronic uncertainty, new information can fail to reduce the ambiguity of their health prognosis (Brashers et al., 2000). However, new information could prompt re-evaluation of an existing uncertainty even if it cannot be reduced. Similarly, additional information may play a role in either reducing or increasing uncertainty depending on the situation. Finally, while uncertainty management does not predict decision-making, it provides a framework for assessing how the decisions are made. The conceptual framework that encompasses these core constructs is presented in Figure 2-1. The main tenets of the
UMT, as well as specific constructs that can affect informed decision making related to participation in clinical research, are discussed next.

Figure 2-1. A conceptual model of decision-making behavior under uncertainty

**Primary Uncertainty Appraisal**

Uncertainty is a complex response to a problematic situation when either the likelihood of outcomes of a particular situation are unknown or when it is not clear how beneficial these possible outcomes would be (Babrow, 1992). Uncertainty creates a problematic, stressful situation that prompts cognitive appraisal (Lazarus & Folkman, 1984). Subsequently, depending on how uncertainty is appraised, coping mechanisms are activated to manage the stressful, uncertain situation (Folkman et al., 1986).

UMT proposes that uncertainty management is accompanied by the appraisal of possible uncertainty outcomes. Once individuals perceive an uncertainty to exist, they engage in the cognitive appraisal process (Brashers & Babrow, 1996). In response to an uncertain situation, individuals can appraise uncertainty as positive (or presenting a potential opportunity for a pleasant, desirable outcome), negative (or threatening to result in an undesirable outcome), or irrelevant to their personal well-being (Babrow & Kline, 2000).

The conceptualization of coping and appraisal developed by Lazarus and Folkman (1984) provided a framework for extensive scholarship related to the understanding of uncertainty, its appraisal, and management. Lazarus and Folkman identify two cognitive appraisal processes. Through the primary appraisal process,
individuals evaluate the stressfulness of a situation in terms of harm, threat, or challenge. The appraisal of harm refers to the perceived loss that has already occurred. Threat refers to the loss that may or is likely to occur because of the situation. Conversely, challenge refers to the understanding that difficulties may be overcome. When uncertainty is appraised as a challenge, some loss is considered as a possible outcome. However, it is viewed as preventable with a possibility of achieving a positive, beneficial outcome. Challenge and threat appraisals are forward-looking, anticipatory evaluations while an appraisal of harm is a backward-looking evaluation based on a known outcome.

Not all new information is appraised as uncertainty that causes some level of stress. A situation can also receive a benign-positive appraisal if the outcome of a situation is perceived to be positive and preserving well-being. This appraisal is associated with pleasant emotions, such as joy, happiness, hope, and peacefulness. However, these emotions are different from those experienced with uncertainty that is appraised as challenge as the latter assumes a possibility of a negative outcome. For example, if the design of a prospective research study does not include randomization into conditions and study outcomes carry the promise of a contribution to science with no personally unwanted outcomes, participation in such a study could be associated with the feeling of joy and hope. However, if the study included either randomization into a less favorable condition or learning about some potentially upsetting information (e.g., cancer risks), participation in such a study would be associated with some possible psychological losses and uncertainty about participation in clinical research.
Secondary Uncertainty Appraisal

Extensive evidence from prior research on self-efficacy suggests its moderating role related to information management and seeking. This secondary appraisal takes place when individuals evaluate their ability to cope with a prospective loss (Lazarus & Folkman, 1984). The labels of primary and secondary appraisal have a firm place in the literature despite the discussion of their falsehood and inadequacy by Lazarus and Folkman. The terms primary and secondary might imply a temporal order for the two appraisal mechanisms. However, as theoretically argued by Lazarus and Folkman (1984), the assumption of such an order is faulty. Another problem with primary and secondary appraisal labels is that they might imply superiority of one appraisal over the other, which was not intended by the development of the labels.

Focusing on the substantive characteristics of the secondary appraisal process, rather than its label, prior studies have identified that it involves the assessment by the individual of his or her ability to cope with uncertainty (e.g., Brashers, 2001; Folkman et al., 1986; M. H. Mishel et al., 1991). This cognitive process allows individuals to assess whether they have sufficient knowledge and skills to address the stressful situation they experience, and if they perceive themselves as having the ability to use these skills. This appraisal, which affects cognitive processes and subsequent behavior, has been most frequently associated with the concept termed self-efficacy introduced by Bandura (1977) in his classic work.

Self-efficacy originally was explicated as a core cognitive mechanism that regulates behavior (Bandura, 1977). Self-efficacy theory differentiates between outcome expectancy and efficacy expectancy. The former is defined as “a person’s estimate that a given behavior will lead to certain outcomes” (Bandura, 1977, p. 193); for example,
an individual’s perception that chemotherapy increases one’s likelihood of surviving cancer would be the outcome expectancy for chemotherapy. The latter, efficacy expectancy, is the individual’s perception of his or her ability to perform the behavior (e.g., to complete the required regimen of chemotherapy sessions) to achieve desired outcomes. Most importantly, the theory makes a prediction that “individuals can believe that a particular course of action will produce certain outcomes, but if they entertain serious doubts about whether they can perform the necessary activities, such information does not influence their behavior” (Bandura, 1977, p. 193).

Bandura argued that an individual’s expectation of personal efficacy, or self-efficacy, plays an explanatory role in fearful and avoidant behaviors and predicts behavioral changes (Bandura, 1977). Self-efficacy affects people's choice of activities and the amount of effort that will be expended to overcome an aversive, stressful situation. Linking directly to coping, Bandura theorized that the strength of perceived self-efficacy is directly and positively related to the more active management of an adversity. Furthermore, persistent management of threatening events is hypothesized to lead to the eventual elimination of stressful appraisal through corrective experience. In other words, those who face and manage uncertainty would acquire the skills to successfully and sustainably manage it. Conversely, those who avoid addressing the stressful situation they face, feeling that they are unable to address and manage it, or those who end their coping efforts prematurely, will retain the fear of the uncertain situation they face and continue engaging in a defensive, rather than managing, behavior.
Evaluating uncertainty-laden messages, health consumers also appraise their coping skills. The perceived efficacy to respond to the uncertainty is theorized to play an essential role in uncertainty management (Lazarus & Folkman, 1984). Specifically, uncertainty can be appraised as a challenge that empowers and gives hope or as a threat that creates feelings of fear, worry, and anxiety. Complex interrelations between appraisal and coping appraisal suggest that self-efficacy has a moderating role in the uncertainty-appraisal relationship. In the context of a decision to participate in clinical research, self-efficacy relates to the perceived ability to find information about study risks and benefits or the ability to make an informed decision.

The skills to manage threatening, uncertain situations can be learned in social contexts through four mechanisms. The most influential efficacy information comes from personal performance and accomplishments. The second source of efficacy to address challenging situations is learning vicariously through the observation of others who perform a coping behavior. Verbal persuasion can also serve as a source of encouragement that the person can successfully perform a coping behavior. Finally, physiological reactance to stress and feeling of anxiety or panic could alter the perception of efficacy for performing a behavior (Bandura, 1977; Lowe et al., 2008).

Generalizability of self-efficacy as a concept allowed its application to communication and information-seeking behaviors. Self-efficacy for health information seeking can be defined as a perceived ability to seek out and find health information when there is a need for it (Basu & Dutta, 2008). Self-efficacy is a perceived skill and differs from the actual ability to get access to information. Health information consumers could have the means to access health information through the Internet but feel anxious
about the possible ambiguity of health recommendations or the volume of health information available to them. According to the 2014 HINTS data, 80% of U.S. adults had visited the Internet to obtain health information in the past 12 months, but only 61% felt completely confident or very confident that they could get health-related information if they needed it (Health Information National Trends Survey (HINTS), 2012).

When appraising uncertainty, individuals assess their resources and capacity for responding to and managing uncertainty (Babrow & Kline, 2000). Within the stress-appraisal-coping framework (Folkman et al., 1986), uncertainty management depends on people’s perceived ability to make independent choices, “particularly when these decisions depend on uncertain outcomes” (Babrow, 2001, p. 558). Individuals may also be uncertain about how to organize and structure information. These appraisals of the capacity to respond to uncertainty, in turn, determine the specific information and uncertainty management behavior (Babrow & Kline, 2000).

Discussing situational differences in the management of uncertainty, UMT recognizes that the availability of communication skills that include seeking and sharing of information as well as cognitive capacity to process and apply it vary from individual to individual. Consequently, individual uncertainty management behaviors will vary from situation to situation (Brashers, 2001). These communication skills, however, can be acquired and subsequently affect information seeking and uncertainty management (Brashers, 2001). The interaction of health-related self-efficacy and evaluative reaction to a health situation has been studied previously (Lee, Hwang, Hawkins, & Pingree, 2008). For example, those who were negatively oriented toward a breast cancer diagnosis but perceived themselves to have higher levels of self-efficacy to respond to
health-related issues were more likely to look for health information about breast cancer than those who reported lower levels of self-efficacy.

The management of uncertainty is closely related to the processing of information related to it. Self-efficacy intervenes in the process of uncertainty appraisal and plays a central role, signaling an individual’s motivation and ability to act on a challenging situation (Rains, 2008). Viewing an uncertain situation through the lens of a potential for personal growth requires a higher level of perceived control and ability to respond to a stressful situation (Skinner, 2014). Connecting primary and secondary appraisal, it could be hypothesized that information-seeking self-efficacy will have a moderating effect on uncertainty appraisal.

H1: Information-seeking self-efficacy moderates uncertainty appraisal. Health consumers with high information-seeking self-efficacy evaluate the uncertainty associated with prospective study participation as a challenge (H1a). Health consumers with low information-seeking self-efficacy evaluate the uncertainty associated with prospective study participation as a threat (H1b).

Uncertainty Management

Mediated communication of information and dissemination of information about clinical research through online channels has a potential to reach wide audiences and support recruitment efforts, but it can lead to confusion (Han, Klein, Lehman, et al., 2011) and information overload (Case et al., 2005) among prospective study participants. Addressing the gap in knowledge and understanding of clinical research, federal agencies, as well as local organizations that conduct clinical research, have created online websites that provide reliable information to health consumers (Friedman et al., 2014). However, the health consumers’ uptake of information from these sites remains low. Substantial research efforts have looked at the features of information
presentation that could lead to higher user engagement. These features, for example, could include the use of narratives, tailoring of information based on specific user characteristics, and use of visuals and videos to increase information richness of communicated messages. The effectiveness of message strategies, however, depends on the uptake of these messages by information consumers and understanding of the causal pathways that lead to information seeking and avoidance.

One goal of communication, as viewed by the UMT, is to provide information consumers with the means to manage uncertainty (Brashers, 2001). The management of uncertainty may include a number of strategies including reduction, maintenance, or increase of uncertainty. Uncertainty management, as a response to uncertainty in its own right, may be a necessity when uncertainty objectively cannot be reduced (i.e., in evaluating participation in a randomized clinical trial). Here, in addition to the need to manage the uncertainty about possible clinical trial outcomes, health consumers also need to manage possible evaluative uncertainty toward participation in clinical research. On the one hand, they may value the progress of medicine and discovery of new drugs and treatments. On the other hand, they may be strongly opposed to enrolling as a volunteer in a study, perceiving participation as a denial of standard-of-care treatment (Biedrzycki, 2010).

Communication and information seeking is a likely response to uncertain information (Brashers, 2001) that, as has been discussed before, has been conceptualized in the extant literature as a quest for uncertainty reduction (Berger & Calabrese, 1975; Bradac, 2001; Gudykunst et al., 1985) and as an approach to uncertainty management (Babrow, 2001; Brashers, 2001; Brashers & Hogan, 2013;
Ford et al., 1996). However, UMT specifically focuses on information behavior as a form of communicative response and an approach to uncertainty management and extends the theory to include information behavior as a theoretical mediator in the process of uncertainty management (Brashers & Hogan, 2013).

The role of uncertainty in information seeking behavior has been conceptualized by the uncertainty management theory (UMT, Brashers, 2001). Uncertainty and its role in information seeking and avoidance have been long recognized as core issues by communication scholars. When feeling uncertain, individuals can react in a number of ways (Brashers, 2001). On the one hand, they might perceive uncertainty as something that threatens their well-being and try minimizing it through information-seeking. On the other hand, they might see uncertainty as something that gives them hope and opportunity to believe that better outcomes are possible, in which case individuals are more likely to choose to maintain their uncertainty by avoiding or seeking for information selectively.

Seeking and consumption of information can facilitate coping with the stress of a health diagnosis (Tluczek, Koscik, Farrell, & Rock, 2005). However, some health situations may lead to different expected outcomes of uncertainty management. Information seeking (Brashers, Goldsmith, & Hsieh, 2002) and participation in active communication with a goal of obtaining social support (Ford, Babrow, & Stohl, 1996) are common behavioral responses to the state of uncertainty that may not see its reduction as the ultimate goal. For example, research about HIV patients showed that some communication behaviors are aimed at uncertainty maintenance, while others seek to increase uncertainty that preserves the feeling of hope (Brashers, 2001). In some other
situations, when uncertainty is chronic and additional information will not reduce it, uncertainty management and coping with uncertainty may become a necessity (Brashers, 2001; Brashers et al., 2002). Similarly, although information seeking might reduce the distress associated with waiting for a conclusive diagnosis, such as learning that one has a genetic disease (Hayeems et al., 2008), new information can carry upsetting news about the severity of a disease and its implications for the lives of patients and their families.

Theoretical and empirical research have identified information behavior as a core uncertainty management strategy (Brashers, Goldsmith, & Hsieh, 2002; Brashers & Hogan, 2013; Mishel et al., 1991). Accepting uncertainty reduction as a valid goal for communicative behavior, UMT argues for a broader view that accounts for situations in which uncertainty leads to hope and optimism (Brashers, 2001). UMT makes three general propositions about the effect of information behavior on uncertainty management (Brashers & Babrow, 1996). Information seeking can decrease uncertainty when possible outcomes become known and some of them become more preferred than others. Alternatively, information seeking can expose health information consumers to new choices and options of varying probabilities and outcome preferences, thus increasing their uncertainty. Finally, by avoiding information, people can maintain their uncertainty.

Health information consumers may seek information to understand their diagnosis and its implications or to become confident about and comfortable with prescribed treatment plans. Preventively, people may seek health information to maintain their health more effectively. Information can be sought from a number of
sources. While physicians are the most trusted source for health information, they are not always the most accessible. Therefore, information consumers may turn to broadcast and print media or, increasingly, to online channels for needed information (Brashers et al., 2002; Rains, 2014).

Information seeking is a common human behavior that can lead to more informed decision-making. When viewed as a danger or threat, uncertainty about an illness may lead to adaptive responses that aim to reduce it (Brashers & Babrow, 1996). By seeking information from health providers, family members, or mediated health information sources, health consumers reduce the uncertainty and get a firmer ground for health-related decision-making. Mediated online sources of information provide additional opportunities and create challenges in the process of uncertainty management because large quantities of (often conflicting) information are available online. The volume and the nature of online health information can be overwhelming for health consumers; getting health information from the Web has been compared to drinking from a fire hydrant (Misra & Stokols, 2012).

Information seeking can also result in discovering upsetting and negative information that cannot be forgotten, or un-known. Information becomes ubiquitous and inescapable, leading to new coping behaviors (Case et al., 2005). This is especially true in situations of uncertainty, in which information seeking is the most common but not an exclusive uncertainty management response (Bradac, 2001; Brashers & Hogan, 2013). Some health consumers develop skills and abilities to actively seek health information and engage with it, while others develop protective coping mechanisms that can create
a barrier to the effective use of health information. These mechanisms include information avoidance, and blunting.

As evidenced by extant research, information avoidance can be a conscious, deliberate behavior (Bradac, 2001; Brashers, 2001; Case et al., 2005). Avoidance has been proposed as another active and intentional information behavior (Brashers et al., 2002; Case et al., 2005). Motivations for uncertainty avoidance can stem from the attempts to maintain hope and optimism in facing a challenging situation (Case et al., 2005). Information avoidance is a purposive information behavior that should be distinguished from the lack of interest in information, or information ignorance. In addition, lack of communication efficacy, or skills to extract relevant health information from an information-dense environment, presents another barrier to active, involved information consumption (Kreps & Neuhauser, 2010; Norman & Skinner, 2006; Tennant et al., 2015). Blunting, one of the active manifestations of information avoidance, occurs when health information consumers choose to focus on information that is not relevant to the health situation they face, effectively distracting them from learning about something that is unpleasant or thinking about threatening and upsetting information (Case et al., 2005).

UMT recognizes information behavior as one of the most frequent uncertainty management and coping strategies. If uncertainty is appraised positively as an opportunity to maintain hope and prevent negative emotions, people are likely to avoid information or be very selective in the amount and content of information they consume (Rains, 2014). Conversely, if uncertainty is appraised negatively as a threat, health consumers are likely to engage in broad information scanning and monitor for cues that
will allow them to reduce their perceived uncertainty (Rains, 2014). As such, information behavior can be conceptualized to have two dimensions, temporal and substantive depth. The former relates to the time information users spend looking for information, and the latter relates to the topics accessed while looking for information.

The relationship between appraisal and information seeking can be conceptually presented by forming the pairs of manifestations of both processes (Figure 2-2). If initially received information is appraised as irrelevant, individuals are unlikely to engage in any information seeking or will engage in limited seeking. If initial information is perceived as uncertainty and appraised as a challenge, individuals are likely to exhibit focused information behavior that would manifest in a small number of accessed topics but relatively large amounts of time spent on these topics. If uncertain information is appraised as a threat, then scanning information behavior is likely. This behavior would be characterized by a large number of topics accessed but relatively little time spent per topic. Finally, information consumers who feel efficacious in managing their uncertainty through information seeking will access a larger number of topics and spend sufficient time to evaluate each topic. Based on this conceptualization, the following hypothesis is formulated:

H2: Uncertainty appraisal predicts information behavior (H2a). Threat appraisal results in health information consumers (H2b) accessing more topics and spending less time per topic than challenge appraisal (H2c).

A relationship between information skills and information behavior has been noted before. Considerable attention has been given to health consumer education in general, and efficacy training in the health communication context has been linked to positive outcomes. Information efficacy skills can be learned through observation and practice. Work by Cegala and colleagues (Cegala et al., 2000, 2001; McGee & Cegala,
provides an example of a successful program that developed and implemented communication skill training for patients in clinical contexts. Cegala and colleagues (Cegala et al., 2000) reported a number of studies that tested interventions to engage patients in information seeking during medical interviews. This work has been prompted by the observation that patients’ information-seeking behavior during conversations with physicians is suboptimal. Although patients state that they want to receive as much information as possible during visits to a medical office, they frequently fail to follow up with health status disclosures or questions about health information.

Figure 2-2. Uncertainty appraisal and information seeking

To address this challenge and provide patients with communication efficacy skills, a training program was developed and evaluated (Cegala, 2003). The training consisted of a mediated communication intervention that patients received at home and during in-office follow-ups. First, patients received training brochures that provided examples of basic questions that could be asked during an office visit. Next, patients were asked to think about the information they wanted to share and questions they wanted to ask. Finally, they were provided with a longer list of possible questions and
encouraged to create their own tailored list of discussion points they would like to bring up during the visit. Upon arrival to the office, patients received a consultation in which they could review their questions and practice discussing them (McGee & Cegala, 1998). Subsequent applications of this approach included only the in-home intervention and have shown effective uptake of communication skills compared to no intervention (Cegala et al., 2001).

H3: Information-seeking self-efficacy predicts and affects the uncertainty appraisal-information seeking relationship (H3a). Health consumers with high information-seeking self-efficacy who appraise uncertainty about participation in a clinical study as a threat spend more time on topics they visit than those with low self-efficacy (H3b). Health consumers with high information-seeking self-efficacy who appraise uncertainty about participation in a clinical study as a challenge engage with more topics than those with low self-efficacy (H3c).

In addition to the stress appraisal of uncertainty, appraisal theory identifies irrelevance as a possible cognitive appraisal route (Lazarus & Folkman, 1984). Irrelevant appraisal takes place when an event is perceived as having no implications for a person’s well-being. When individuals are not involved in the possible outcomes, they perceive that situations under appraisal have no effect on their values, needs, or commitments because irrelevant situations carry no possible gains or losses.

The examination of cognitive processes that result in such an appraisal identified the need for cognition as a construct that provides explanation. Early psychological research showed that individuals high in need for cognition expended greater effort on message processing (Petty, Cacioppo, & Kao, 1984). Specifically, one study showed that those with high need for cognition gathered more information and attended to more aspects of the situation about which they needed to make a decision (Nair & Ramnarayan, 2000). Whereas appraisal of uncertainty could provide an explanation for
the situational systematic processing of information, the need for cognition can be viewed as a dispositional factor that affects information behavior (A. J. Rothman, Bartels, Wlaschin, & Salovey, 2006).

H4: Need for cognition predicts the appraisal-information seeking relationship.

**Uncertainty about Cancer and Clinical Research**

The decision to participate in a clinical study is associated with a number of uncertainties. When health consumers consider a decision to participate in a clinical research study, they frequently face the chance of being randomly assigned to a study arm that may be less desirable than other study arms. The prospective of randomization presents a 50/50 chance of an outcome (for a two-arm study) and implies not knowing what outcomes will be achieved. The uncertainty is the lowest when there is a 100% chance of something occurring or a 0% chance of something occurring. However, when there is a 50% chance of achieving the desired outcome, uncertainty is the highest (Brashers, 2001; Mishel, 1984). This curvilinear function of uncertainty makes randomization the most objectively uncertain state that contributes to probabilistic uncertainty when the answers to the questions about specific outcomes of participation in a clinical study are unknown.

A different kind of uncertainty could be caused by the evaluation of whether the occurrence of a particular situation is good or bad. Whether a clinical study is randomized or not, prospective participants must assess the possibility of experiencing discomfort or facing unpleasant procedures if they choose to participate. Depending on the situation, individuals may face uncertainty about the likelihood of the outcomes, uncertainty about whether participation in a clinical study is good or bad, or both. In
addition to the need to manage the uncertainly about possible clinical trial outcomes, health consumers also need to manage possible evaluative uncertainty related to participation in clinical research. On the one hand, they may value the progress of medicine and discovery of new drugs and treatments. On the other hand, they may be strongly opposed to enrolling as a participant in a study. For example, a patient may avoid cancer screening because the information that he or she will learn could be threatening and upsetting. Here, evaluative uncertainty forms when an individual is faced with the question, “Is learning about my cancer risks good or bad?”

No event exists in a vacuum or undergoes fully independent consideration for decision-making. Uncertainty about events that are closely related to each other may create chaining, or a situation in which uncertainty about one event increases uncertainty about the other (Babrow, 2001). Possible chaining of two causes of uncertainty has been addressed within the framework of problematic integration theory (PIT, Babrow, 1992, 2001). PIT argues that communication is a mechanism that shapes and transforms probabilistic and evaluative orientations and integrates them with one another. The former relates to the understanding of facts associated with uncertain information, and the latter refers to the need to reconcile positive and negative reactions to the source of uncertainty.

PIT was developed in consideration of the relationship “between communication and one’s conception of or orientation to the world” (Babrow, 2001, p. 554). Although the theory came about as a general perspective on communication, substantial scholarship on its development (Babrow, 1992, 2001; Babrow & Kline, 2000) and application (E. L. Cohen, 2009; Dennis, Kunkel, & Keyton, 2008; Ford et al., 1996; Gill &
Babrow, 2007; Repass & Matusitz, 2010; Sharf, Stelljes, & Gordon, 2005) has occurred within the field of health communication.

To provide a general perspective on communication, PIT makes several propositions. First, it posits that people form probabilistic and evaluative orientations when developing worldviews and mental models of uncertainties that surround them. Probabilistic orientation encompasses one’s understanding of some event or object of thought. This orientation focuses on the nature and understanding of facts and features and answers questions like, “What does this seem to be? What are its characteristics? How is it likely to behave?” (Babrow, 2001). Evaluative orientation assigns values to objects and events and answers questions like, “Is this object, characteristic, event, or outcome good or bad?” (Babrow, 2001).

Probabilistic and evaluative orientations are integrated and interdependent and shape people’s perceptions of life experiences. The integration of probabilistic and evaluative orientations merges the probability and value of experiencing or avoiding an uncertain event. Such integration affects subsequent decision-making, intentions, and behavior related to an event. Yet, as one of the PIT propositions claims, the integration of these two orientations is frequently problematic (Babrow, 1992, 2001). As an object’s probabilities and the values assigned to it change, they may destabilize each other. For example, perceived scarcity of an object may either increase or decrease its value, and perceived value may influence the judgment of the object occurrence either through optimistic bias or defensive rationalization (Babrow, 2001).

The problematic integration or orientation toward one object may be transformed through re-evaluation, and the probability-evaluation relationship can change as new
information is encountered and evaluated (Babrow, 2001). Uncertain situations could be caused by both probabilistic and evaluative uncertainty. However, these uncertainties do not have to be related to the same phenomenon. Additionally, uncertainty about one situation can activate uncertainty about another situation in a chain reaction. Uncertainty about an object may also be re-evaluated and shift to another, connected focus. For example, one’s uncertainty about personal cancer risk information may heighten uncertainty about participation in a research study. For example, a person might first perceive something as highly improbable, e.g., development of a treatment for an incurable disease, but later see it through the prism of hope. Uncertainty about an object may also be re-evaluated and shift to another, connected focus. For example, one’s uncertainty about participation in a clinical trial may heighten awareness of one’s poor health status and activate associated worries.

Finally, PIT suggests that communication content, structure, and processes shape and transform problematic integration of probabilities and values. Communication can be the source of problematic integration because new information may challenge and shape problematic and evaluative orientations, or it could provide means and resources for coping with uncertainty.

H5. Uncertainty forms show chaining effects. The presence of probabilistic uncertainty related to cancer risk information results in decisional conflict related to participation in clinical research (H5a). The presence of evaluative uncertainty related to randomization results in decisional conflict related to participation in clinical research (H5b). Probabilistic and evaluative uncertainty interact to predict decisional conflict related to participation in clinical research (H5c).

Exposure to information can activate people’s interest in a particular topic and have an effect on their information seeking behavior. The earlier stated theoretical assumption proposed that uncertainty perceived by an individual can result in
information seeking that aims to manage that uncertainty (Brashers et al., 2002).

Therefore, different sources of uncertainty, e.g., randomization or information about
cancer risks, could result in different topical interests. It could be expected that
participants invited to participate in randomized and non-randomized studies will differ in
their interest toward the topics about the basics of clinical research that also include
randomization. Similarly, it could be expected that individuals who experience
uncertainty related to learning about their possible cancer risks will have different
evaluation of information related to cancer basics compared to those whose thought
about cancer and a perspective of received good or bad news has not been activated.

Earlier studies attempted to identify topical differences in information seeking
(Rains & Tukachinsky, 2015) but did not uncover any conclusive evidence. While it
could be expected that different types of uncertainty will lead to situational differences in
information seeking, there is not enough evidence to formulate hypotheses. Therefore,
the following research question will be investigated:

RQ1: What are the characteristics of content that lead to differences in
information behavior among health consumers who experience
probabilistic uncertainty related to randomization or evaluative uncertainty
related to cancer risk information?

Sociocultural Considerations

Gender differences

Currently, women are underrepresented in clinical studies (Melloni et al., 2010).
Some of this disparity could be explained by external factors, such as study exclusion. A
comprehensive systematic review of clinical studies published in high-impact journals
showed that female sex was the reason for exclusion in some 39% of the reported
protocols.
Other reasons for underrepresentation in clinical research could relate to the appraisal of possible study outcomes and their effects on willingness to participate in research (Ellis, Butow, Tattersall, Dunn, & Houssami, 2001). Ellis and colleagues (2001) showed that women who would consider participating in an oncology clinical study valued the prospective positive outcomes and were less likely to focus on the negatives and losses that could be possible. Evaluation of the role of gender in the cognitive appraisal suggests that males are more likely to appraise uncertain situations as a challenge, and females are more likely to appraise uncertainty as a threat (Ptacek, Smith, & Zanas, 1992). Additional investigation of the role of gender in the appraisal of stressful events looked at the differences in general, dispositional and situation-specific responses (Sigmon, Stanton, & Snyder, 1995). For the dispositional cognitive appraisal, the study by Sigmon and colleagues confirmed that males are more likely than females to perceive stressful events as challenging. However, the study reported mixed findings for situational appraisal.

In addition to cognitive appraisal differences, Ellis et al. showed that women who have better knowledge about clinical research and understand randomization are more likely to participate (Ellis et al., 2001). Similarly, other studies have identified that increased general and study-specific knowledge about clinical research has a positive effect on participation in clinical research (Byrne, Tannenbaum, Glück, Hurley, & Antoni, 2014; Kim et al., 2015).

The Internet provides quick access to information and is increasingly used by healthcare organizations to disseminate information about clinical research. This strategy could lead to fruitful results as 72% of those who use the Internet have looked
for some kind of health information (Fox, 2013). Although men and women are as likely to access the Internet (Pew Research Center, 2014), women are more likely to search for and engage with health information online (Kontos, Blake, Chou, & Prestin, 2014). While previous research did not provide enough evidence to formulate hypotheses that link gender, uncertainty appraisal, and information seeking, this relationship warrants future investigation.

RQ2. How do males and females differ in uncertainty appraisal related to participation in a clinical research study?

RQ3. To what extent does gender predict the relationship between appraisal and information seeking?

Race and trust in medical researchers

Participation of minorities in clinical research has been noted previously as a serious shortcoming for the progress of and a barrier to the generalizability of clinical research (Lara et al., 2001; Mouton, Harris, Rovi, Solorzano, & Johnson, 1997). Several national-level policy initiatives have been undertaken to address this issue (Centers for Medicare and Medicaid Services, 2006; National Institutes of Health, 2001; U.S. Food and Drug Administration, 2014). However, minorities are still significantly underrepresented in most clinical research studies (George, Duran, & Norris, 2014).

Mistrust in medical researchers has been named as a key barrier to the successful dissemination of health information and enrollment of minority study participants in health-related research (Moreno-John et al., 2004; Murthy et al., 2004). The Tuskegee study is the most infamous, but unfortunately not the only, example of the reasons for mistrust in medical researchers among minority patients. The Tuskegee Syphilis Study was undertaken in 1932 to study the effects of untreated syphilis in 399
African American men from rural Alabama, and the study continued until 1972 although effective treatment of syphilis became available in the 1940s (Rothman, 1982).

H6: Trust in medical researchers affects the relationship between race and information behavior.

African American participants are as likely as Caucasians to express intentions to participate in clinical research (Wendler et al., 2005), and some institutions have been successful in recruiting minority participants at rates over-representing the general population (Fisher & Kalbaugh, 2011). However, the evidence for mistrust toward medical research among prospective minority participants is mixed. Some surveys show that African Americans express less support for medical institutions in general and are less likely than Caucasian participants to trust that medical researchers will explain and disclose all the details of study protocols (Wendler et al., 2005). In addition to the possibility of lower trust in medical researchers and healthcare institutions, recent reports on the use of online information sources report that African Americans are less likely to look for information—including health information—online, yet the race-based digital divide no longer explains this difference (Kontos et al., 2014). One study showed that in the context of clinical interactions, African American patients were less likely to ask questions than Caucasian patients (Eggly et al., 2011). This evidence suggests that information behavior and active information seeking could play a role in the low participation of minorities in medical research.

H7. African Americans are less likely than Caucasians to seek information about clinical research.

H8: Race, trust in medical researchers, and information-seeking self-efficacy predict information seeking (H8a) and behavioral intention to participate in clinical research (H8b).
Decision-making and Participation in Clinical Research

Ethical standards for the conduct of clinical research require informed decision making on the part of prospective study participants. However, there are a number of challenges to achieving truly informed participation, including cognitive and emotional factors. Therefore, understanding the mechanisms of decision-making offers opportunities for improved and sustainable decision support.

Decision theory has a number of applications and, coming from a number of research traditions, proposes multiple ways to understand and develop theoretical understanding of decisions and choices. As such, decision theory makes a distinction between normative and descriptive theories. A normative decision theory aims to explain how decisions, guided by rational evaluation of options, should be made to achieve the most optimal outcome. In contrast, a descriptive theory is a theory that looks at how decisions are actually made, what biases may have played a role, and which shortcuts consumers may be taking in selecting their preferred option. It is important to note that the normative view has a focused meaning in decision theory. It applies exclusively to the norm of rationality. This understanding does not take into account social or ethical norms, which need to be addressed first. However, the line between the two types of theories gets blurry when decision-makers make suboptimal choices without being irrational.

Most scholars agree that a decision process involves several stages. One of the popular models to describe the stages of decision-making was proposed by Orville Brim and his colleagues (see Baron, 2005). The model includes five stages of decision-making process: (1) identification of the problem, (2) obtaining necessary information, (3) production of possible solutions, (4) evaluation of solutions, and (5) selection of a
strategy for performance (i.e., formulating an intention to take a specific action). Other authors have argued that the process of decision-making could not be described through neatly separated stages. Instead, decision-makers may go through a circular re-evaluation of information about choices, seek new information, identify new possible choices, and re-evaluate their preferences and assessment of these choices. The second option comes with new information, new possible solutions, and their evaluation. The decision-making process, however, is finite, and at the end, a decision-maker makes a choice to obtain the perceived best possible outcome, based on some evaluation of outcome values.

Decision-making about participation in clinical research is no simple matter. On the one hand, participation of human subjects is necessary to develop and evaluate much-needed treatments for cancer and other diseases. This notion is promoted by international (WHO) and national organizations (NIH, NCI) and supported by lay health consumers (Byrne et al., 2014; Wendler et al., 2005). Altruism and understanding that volunteer participation in clinical research is necessary for the health of other patients is one of the strongest reasons for participation (McCann, Campbell, & Entwistle, 2010). Participation in clinical research could also lead to beneficial outcomes for participants who can learn about their health, get access to a treatment not available otherwise, or participate in novel health promotion activities. On the other hand, decisions to participate in clinical research studies involve evaluation of a possibility of potential unwanted outcomes (Ellis et al., 2001). Randomization into a treatment--or non-treatment--condition and the side effects of experimental treatment can be viewed as
negative outcomes of participating in a clinical study (Byrne et al., 2014; George et al., 2014).

Prospective participants face different kinds of decisions along the clinical research participation process from initial recruitment and contact with a research team to consent to participate in a study and to continuous participation and completion of the study activities. The link between uncertainty and decision-making has been explored and established before (O’Connor, 1995). Therefore, in the context of enrollment in clinical research, perceived uncertainty could manifest as decisional conflict about participation in a clinical study. A number of reasons could explain why people are not optimal decision makers along all steps of this process. Although the ultimate decision related to participation in clinical research has two possible outcomes, to participate or not to participate, situational characteristics of these decisions vary among prospective participants and are based on the types of clinical studies. However, informed choice rather than a positive decision to participate in a clinical study should be the goal of recruitment activities. The decision-making process that accounts for the role of self-efficacy and uncertainty appraisal is conceptually presented in a moderated mediation model of informed decision-making (Figure 2-3).

![Figure 2-3. An explanatory model of informed decision-making](image)

The UMT theory focuses on the role of communication and provides an insight into the process of uncertainty management. The theory implies the effect of uncertainty
management on decision-making and behavior but does not offer any specific predictions about behavior. Rather, it emphasizes the situational nature of uncertainty management. Scholarly literature and evidence from theory-driven research on consumer decision-making under the conditions of risk and uncertainty offer some practical and useful findings and implications. In the increasing volume of information that consumers are exposed to on a daily basis, focused, evidence-based strategies are likely to be more effective in communicating about the attributes and uses of advertised products and services. Theoretical developments and scholarly research will also continue to play a role in guiding the development of advertising messages and provide advanced understanding of the content, processes, and effects of communication on informed consumer choice.

As an extension of the UMT, the model presented above makes a connection between uncertainty appraisal and information behavior and proposes an explicit moderating role for self-efficacy. Furthermore, the UMT recognizes the role of uncertainty appraisal in the process of uncertainty management and underscores that uncertainty is re-appraised as individuals engage in communication, encounter new information, and use the information to increase, decrease, or maintain their state of uncertainty (Brashers, 2001). The proposed moderated mediation model, therefore, assigns a mediating role to uncertainty appraisal as it relates to information behavior and decision-making. Building on the understanding that the process of uncertainty management results in re-evaluation of the object or event that caused uncertainty, the proposed model also proposes that uncertainty appraisal acts as a mediator that may explain differences in information behavior. Theoretical relationships among perceived
uncertainty, information-seeking self-efficacy, uncertainty appraisal, information seeking, and decision making exhibited through behavioral intention allow formulating the following hypothesis:

H9. Decisional conflict, uncertainty appraisal, and information seeking (H9a) and avoidance (H9b) comprise a model of situational decision-making in the context of recruitment for clinical research.

**Hypotheses and Research Questions**

Theory has a role in both research and practice. If “theory building is a means of organizing and systematizing what is known as well as identifying potentially fruitful directions for future research” (Brashers & Babrow, 1996, p. 244), UMT is ripe for empirical testing. UMT has been used in numerous studies as the main theoretical framework, but with a few exceptions (Rains, 2014; Rains & Tukachinsky, 2015), most of these studies were interpretive and used qualitative methods.

UMT provides propositions about the situational and fluid nature of uncertainty management and can inform the practice of health communication under uncertainty. While providing a strong theoretical foundation and explanatory propositions, the theories do not supply predictive hypotheses to explain individual behavior under uncertainty. To address this need and extend the application of the UMT, a moderated mediation model of informed decision-making is proposed and several possible covariates are identified.

Hypotheses and research questions for this study were introduced throughout Chapter 2 and are also listed below. Figure 2-4 schematically shows the hypotheses and research questions in relation to the constructs proposed for examination.

H1: Information-seeking self-efficacy moderates uncertainty appraisal. Health consumers with high information-seeking self-efficacy evaluate the uncertainty associated with prospective study participation as a challenge
(H1a). Health consumers with low information-seeking self-efficacy evaluate the uncertainty associated with prospective study participation as a threat (H1b).

H2: Uncertainty appraisal predicts information behavior (H2a). Threat appraisal results in health information consumers (H2b) accessing more topics and spending less time per topic than challenge appraisal (H2c).

H3: Information-seeking self-efficacy predicts and affects the uncertainty appraisal-information seeking relationship (H3a). Health consumers with high information-seeking self-efficacy who appraise uncertainty about participation in a clinical study as a threat spend more time on topics they visit than those with low self-efficacy (H3b). Health consumers with high information-seeking self-efficacy who appraise uncertainty about participation in a clinical study as challenge engage with more topics than those with low self-efficacy (H3c).

H4: Need for cognition predicts the appraisal-information seeking relationship.

H5. Uncertainty forms show chaining effects. The presence of probabilistic uncertainty related to cancer risk information results in decisional conflict related to participation in clinical research (H5a). The presence of evaluative uncertainty related to randomization results in decisional conflict related to participation in clinical research (H5b). Probabilistic and evaluative uncertainty interact to predict decisional conflict related to participation in clinical research (H5c).

H6: Trust in medical researchers affects the relationship between race and information behavior.

H7. African Americans are less likely than Caucasians to seek information about clinical research.

H8: Race, trust in medical researchers, and information-seeking self-efficacy predict information seeking (H8a) and behavioral intention to participate in clinical research (H8b).

H9. Decisional conflict, uncertainty appraisal, and information seeking (H9a) and avoidance (H9b) comprise a model of situational decision-making in the context of recruitment for clinical research.

RQ1: What are the characteristics of content that lead to differences in information behavior among health consumers who experience probabilistic uncertainty related to randomization or evaluative uncertainty related to cancer risk information?
RQ2. How do males and females differ in uncertainty appraisal related to participation in a clinical research study?

RQ3. To what extent is gender a predictor of the appraisal-information seeking relationship?

Figure 2-4. Study hypotheses and research questions
CHAPTER 3
METHODS

Procedures

The research protocol was approved by the behavioral science Institutional Review Board at the University of Florida, IRB-02. Once participants have been invited to participate through a consumer survey panel, SSI, they were provided with a link to the survey. First, they read and electronically signed an informed consent and answered questions about their age, gender, and education level to confirm their eligibility. The rest of the survey elements were related to covariate measurement, message and self-efficacy manipulations, information behavior observation, and dependent variable measurement.

Participants were randomly assigned to read one of the four study recruitment messages. They then answered questions about their uncertainty, which was operationalized as decisional conflict, related to participation in the advertised study and cognitive appraisal of uncertainty associated with the advertised studies. Next, they were randomly assigned to either read about and comment on the benefits of information seeking or the challenges of information seeking. All participants were then provided access to an information website, asked to explore it, and encouraged to read messages that interested them. Participants had an opportunity to explore questions and answers about clinical research, cancer, and daily use of aspirin. Next, participants were asked to report whether they were seeking or trying to avoid information related to clinical research. Finally, participants answered behavioral intention questions about participation in a clinical study.
Participants

Participants were recruited through an existing, nationally representative online research panel provided by SSI. Participants were invited to participate in the study and screened prior to participation. Purposeful sampling was used to test hypotheses based on demographic variables. All recruited participants were more than 18 years old. The sample was stratified by gender (50% male and 50% female) and race (50% Caucasian and 50% African American). This purposeful sampling allowed the researcher to address some of the limitations noted by previous online experiments related to lower participation of males, minorities, and those with lower educational levels (e.g., Shapiro, Chandler, & Mueller, 2013; Strekalova, 2014). Based on the sample size estimates presented in the Power Analysis section, 340 participants were recruited for participation in the online survey. For completion of surveys, participants received reimbursement from SSI in the form of bonuses and cash equivalents.

Materials

Message Stimuli

A sample recruitment message is shown in Figure 3-1, and all four recruitment message manipulations can be seen in Appendix A. A manipulation of probabilistic uncertainty was achieved by exposing participants to a recruitment message for a quality improvement study (low probabilistic uncertainty) or a randomized clinical trial (high probabilistic uncertainty) for healthy volunteers. To manipulate evaluative uncertainty, recruitment messages either included information in which participants learned about their personal cancer risks (high evaluative uncertainty) or not (low evaluative uncertainty).
Information-seeking Self-efficacy Manipulation

The information-seeking self-efficacy manipulation included three cognitive elements that are theorized to provide information about an individual's efficacy, i.e., exposure to a persuasive message, vicarious experience with behavior through observation, and self-reflection and practice of skills (Bandura, 1977). Participants were randomly assigned to high- or low-efficacy condition. Participants in the high self-efficacy condition read a short message suggesting that careful evaluation of health information helps in making informed decisions about participation in health-related studies and that make people like them make these decisions every day. Next, they were provided with a list of possible questions and information topics they could pursue.
to learn about clinical research and encouraged to pick a few questions that interested them most. Finally, participants were asked, on their own, to write one or two questions or topics related to clinical research that they found personally interesting and relevant. Once done, participants saw a new screen with personalized information containing the list of questions they had selected and questions or topics they had just written. The list of sample questions was based on the topics that were subsequently provided to study participants through the study information site. Sample questions included paraphrased versions of the questions answered on the information site.

Similarly, participants in the low-efficacy condition were informed that making a decision to participate requires analyzing a lot of conflicting and confusing information and that these decisions are never easy. These participants were presented with a list of statements that represent challenges associated with looking for information online. Finally, they were asked to write why information about clinical research is complex and what challenges they faced the last time they tried to find health information online. Messages and free-text question prompts are presented in Appendix B.

**Information Seeking**

An information-seeking tool was created within the Qualtrics survey platform to provide information about cancer, clinical research, and daily use of aspirin. Cancer information was adapted from the National Cancer Institute (National Cancer Institute, 2015) and American Cancer Society (American Cancer Society, 2016). Clinical research topics were adapted from the American Society of Clinical Oncology site (American Society of Clinical Oncology, 2016), and information about aspirin was adapted from the NIH MedlinePlus website (U.S. National Library of Medicine, 2016).
All participants were provided access to the same information. Participants were sequentially exposed to three pages and asked to choose any number of available information topics related to cancer, clinical research, and daily use of aspirin. Second-level pages contained answers to the selected questions. Time spent on each second-level page was captured and collected through embedded Qualtrics meta-data fields. The list of page questions and topics is presented in Appendix C.

Survey Instrument

A summary of variables used in this study is presented in Table 3-1. Information about individual scale items and previous reliability values follows the table. Unless otherwise noted, instrument items were measured using a 7-point Likert-type scale with anchors “very strongly disagree” (1) and “very strongly agree” (7).

Demographic Variables and Covariates

Sociodemographic data

Sociodemographic data were collected to account for differences between conditions and outcome variations due to participant characteristics. Sex (male or female), age (in years), race (Caucasian/White, African American/Black), ethnicity (Hispanic/non-Hispanic), education (less than high school, some high school, high school/GED, some college, college graduate, post-graduate), income (US$) (less than $20,000, $20,000-$49,999, $50,000-$99,999, $100,000 or more), and marital status (married, separated, divorced, widowed, never been married) were assessed.
Table 3-1. List of variables and measurement instruments

<table>
<thead>
<tr>
<th>Variable</th>
<th>Measurement Instrument</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Demographic Variables and Covariates</strong></td>
<td></td>
</tr>
<tr>
<td>Sociodemographic data</td>
<td>Age, gender, marital status, race, ethnicity, income, education (HINTS, 2014)</td>
</tr>
<tr>
<td>Cancer and health status</td>
<td>One item adapted from HINTS (HINTS, 2014) and two cancer status questions</td>
</tr>
<tr>
<td>Need for cognition</td>
<td>18-item scale (Petty et al., 1984)</td>
</tr>
<tr>
<td>Issue involvement</td>
<td>15-item semantic differential Personal Involvement Inventory (Zaichkowsky, 1985)</td>
</tr>
<tr>
<td>Autonomous decision-making</td>
<td>6-item Decision-making Preference Subscale of the Autonomy Preference Index (Ende, Kazis, Ash, &amp; Moskowitz, 1989)</td>
</tr>
<tr>
<td>Knowledge about clinical trials</td>
<td>7-item scale (Ellis et al., 2001)</td>
</tr>
<tr>
<td>Trust in medical researchers</td>
<td>12-item scale (Hall et al., 2006)</td>
</tr>
<tr>
<td><strong>Independent Variables/Manipulation Checks</strong></td>
<td></td>
</tr>
<tr>
<td>Message comprehension</td>
<td>2-item scale (Kalichman &amp; Coley, 1995)</td>
</tr>
<tr>
<td>Probabilistic uncertainty</td>
<td>Study-specific 4-item scale</td>
</tr>
<tr>
<td>Evaluative uncertainty</td>
<td>Study-specific 4-item scale</td>
</tr>
<tr>
<td>Information-seeking self-efficacy</td>
<td>8-item eHealth Literacy Scale (eHEALS) (Norman &amp; Skinner, 2006)</td>
</tr>
<tr>
<td><strong>Mediator and Moderator Variables</strong></td>
<td></td>
</tr>
<tr>
<td>Decisional conflict</td>
<td>3-item Decisional Conflict Uncertainty Subscale (O'Connor, 1995)</td>
</tr>
<tr>
<td>Cognitive uncertainty appraisal</td>
<td>9-item scale including threat and challenge subscales (Rains &amp; Tukachinsky, 2015)</td>
</tr>
<tr>
<td>Affective uncertainty appraisal</td>
<td>6-item scale including threat and challenge subscales (Rains &amp; Tukachinsky, 2015)</td>
</tr>
<tr>
<td>Information behavior</td>
<td>21-item topic selection measurement (observational measure)</td>
</tr>
<tr>
<td>Information behavior</td>
<td>4-item self-reported behavior scale adapted from (Barbour, Rintamaki, Ramsey, &amp; Brashers, 2012) and 2 free-text questions about information sought/avoided</td>
</tr>
<tr>
<td><strong>Dependent Variable</strong></td>
<td></td>
</tr>
<tr>
<td>Behavioral intention</td>
<td>2-item scale including a global item and an implementation intention item (Armitage &amp; Conner, 2000; Gollwitzer &amp; Brandstätter, 1997)</td>
</tr>
</tbody>
</table>
Health status and cancer history

Perceived health status was measured using one question adapted from the Health Information National Trends Survey (HINTS; Health Information National Trends Survey, 2014) using a 7-point scale with the following anchors: “poor” (1) and “excellent” (7). Cancer health status was measured using two questions adapted from the HINTS. Personal history of cancer was assessed with the question “Have you ever been diagnosed as having cancer?” with answer options Yes or No. Family history of cancer was assessed with the question “Have any of your family members ever had cancer?” with answer options Yes, No, or Not Sure. Personal and family history of cancer were evaluated as covariates in subsequent analyses.

Need for cognition

Need for cognition does not necessarily improve the quality of decision making but has been shown to explain individuals’ intrinsic motivation for spending time on working with cognitively challenging tasks (Låg, Bauger, Lindberg, & Friborg, 2014). The original 34-item Need for Cognition scale was developed to measure the tendency for an individual to engage in thinking about challenging or new information (Cacioppo & Petty, 1982). Subsequently, the scale was reduced to the 18-item format (Petty et al., 1984). The latter version of the scale has been used extensively in a number of situations including health decision-making (e.g., Slovic et al., 2005) and health-related information processing (Williams-Piehota, McCormack, Treiman, & Bann, 2008).

Autonomous decision-making

Autonomy preference was measured with a 10-item scale adapted from Ende and colleagues (Ende et al., 1989). The original scale included a six-item decision preference scale, three-item vignettes associated with specific health conditions and
illnesses and an eight-item information-seeking preference scale. In the decision to participate in clinical research, doctors and families have been identified to play an important role. Therefore, the autonomy preference scale for this study included similar items to measure autonomy preference related to doctor’s and family’s participation in the decisions. Responses were measured using a five-point scale with anchors “completely disagree” and “completely agree.” To assess autonomy preference, participants provided responses to statements like “My family/doctor should decide if it is good for me to participate in a clinical study.”

Ende and colleagues recognize information-seeking preferences as a sub-construct of the preference for autonomous decision-making (Ende et al., 1989). In this study, adapted to focus on decisions related to participation in clinical studies, information-seeking preference related to autonomous decision-making were measured on a 7-point scale with anchors “very strongly disagree” and “very strongly agree” for the items that focus on information about the details of a clinical study and its outcomes.

**Issue involvement**

Participants were asked to use a 15-item semantic differential Personal Involvement Inventory (Zaichkowsky, 1985) to indicate how they felt about the advertised clinical study, e.g., important/unimportant, useful/useless, of concern to me/of no concern to me. Answers were scored using a 7-point scale.

**Knowledge about clinical trials**

The seven-item Knowledge Scale was developed by Ellis et al. (Ellis, Butow, Tattersall, Dunn, & Houssami, 2001) and used for the assessment of clinical trial knowledge among a sample of women attending a breast cancer screening clinic and women newly diagnosed with breast cancer. Scale items use general terms that test for
the understanding of the clinical trial process, e.g., “In a randomized trial the treatment you get is decided by chance”; “Randomized trials are the best way to find out whether one treatment is better than another.” Participants were asked to assess each statement as true or false or to indicate that they did not know the response. The number of correct responses were summed up to give a knowledge score that could range from 0 to 7.

**Trust in medical researchers**

Trust in medical researchers was measured using the 12-item scale developed by Hall et al. (2006). The scale uses items that focus on trust in doctors doing medical research (e.g., “I completely trust doctors who do medical research”; “Some doctors do medical research for selfish reasons”) and trust in medical research or researchers generally (e.g., “Medical researchers have no selfish reasons for doing research studies”; “There are some things about medical research that I do not trust at all”). Scale evaluation using a sample of community participants showed a high level of reliability (Cronbach’s alpha = 0.87).

**Independent Variables and Manipulation Checks**

**Message comprehension**

In order to demonstrate that the framing of messages does not affect the readability or comprehensibility of the messages, two items, adapted from Kalichman and Coley (1995), were included to assess the extent to which recruitment messages were difficult or easy to read and understand. The items were presented as follows:

- The message was easy to read
- The message was easy to understand
Probabilistic and evaluative uncertainty

The most robust and frequently used measure of uncertainty is the Mishel Uncertainty in Illness Scale (MUIS). The original scale consists of 34 Likert scale items representing four subscales: ambiguity, complexity, lack of information, and unpredictability. The scale asks patients to respond to statements related to their illness and health management. Shorter scales have also been developed for the assessment of uncertainty related to chronic illness and for use in community settings. The MUIS has been used extensively to assess health-related uncertainty, but the scale is limited in its ability to distinguish between the probabilistic and evaluative components of uncertainty. Furthermore, the scale focuses on the experiences of a medical patient and uncertainty related to an experienced state of illness. The hypotheses for the current study aim to evaluate uncertainty related to a decision to participate in a clinical research study and uncertainty about possible outcomes of that decision.

Following the conceptualization of uncertainty proposed by Babrow, two new scales were created to measure probabilistic uncertainty about future study-related events (i.e., assignment to a particular study group) and evaluative uncertainty related to potential exposure to cancer risk information. Two 4-item scales were created to measure uncertainty related to probabilities and values. Items included in the probability uncertainty measure were informed by previous research related to perceptions of study participants toward randomization (Biedrzycki, 2010; Mills et al., 2006) and formulated as follows:

If I participate, my study group assignment will be determined by chance
If I participate, my study group assignment is unknown

If I participate, my study group assignment will be randomly selected
If I participate, my study group assignment won’t be known in advance
Items included in the evaluative uncertainty measure were informed by previous research and scales developed to measure ambivalence about available options (Armitage & Conner, 2000; Thompson et al., 1995). As a construct, ambivalence has been linked to uncertainty as it represents a state in which an event is evaluated as possibly leading to both positive and negative outcomes (Babrow, 2001), which most closely represents the uncertainty that prospective clinical study participants may experience in evaluating risks and benefits of a study. Evaluative uncertainty items were formulated as follows:

Information that I will learn in this study can be either good or bad for me
Information that I will learn in this study can be either pleasant or unpleasant for me
Information that I will learn in this study can be either favorable or unfavorable for me
Information that I will learn in this study can be either beneficial or harmful for me

**Decisional conflict**

To measure perceived uncertainty related to participation in a clinical study and assess the role of probabilistic and evaluative uncertainty as its predictors, uncertainty items from the Decisional Conflict Scale were used in this study (O’Connor, 1995). Participants received a prompt, “Questions below relate to participation in the advertised research study. Please indicate if you agree or disagree with the statements below.” Scale items presented below were measured on a 7-point scale with anchors “strongly disagree” (1) and “strongly agree” (7) and subsequently reverse-coded to associate greater values with a higher level of decisional conflict.

I was clear about the best choice for me
I felt sure about what to choose
This decision was easy for me to make
**Information-seeking self-efficacy**

Self-efficacy is a robust construct that was originally proposed as a measure of a core psychological trait and belief in one’s ability to perform an action (Bandura, 1977); subsequently, it has been applied and further developed for situational applications. This study focuses on the role of information seeking in uncertainty management. Therefore, self-efficacy for this study is operationalized as the perceived ability to look for and identify helpful information on the Internet.

The eHealth Literacy Scale (eHEALS) was used to assess information-seeking self-efficacy. The eHEALS was developed to assess health information consumers’ perceived ability to find and use information in mediated contexts (Norman & Skinner, 2006). The eHEALS is a single-factor 8-item scale that determines consumers’ combined knowledge, confidence, and perceived skills in finding, evaluating, and applying electronic health information to health problems (Norman & Skinner, 2006). Previous application of the scale showed high internal consistency (alpha = .88 and higher) (Choi & DiNitto, 2013; Norman & Skinner, 2006). The scale was originally developed and validated using a sample of participants aged 13-21 (Norman & Skinner, 2006) but subsequently has been used in a number of studies involving adult and older adult populations (Choi & DiNitto, 2013; Xie, 2011).

**Mediator and Moderator Variables**

**Uncertainty appraisal**

Conceptually, appraisal of stressful situations can manifest in harm, threat, and challenge appraisals (Lazarus & Folkman, 1984). Harm appraisal implies losses that have taken place and has been consistently excluded from evaluation of the appraisal of forward-looking behaviors (Mishel et al., 1991; Rains & Tukachinsky, 2015).
Operationally, these appraisals include a cognitive component (i.e., the assessment of an anticipated loss or gain) and an affective component (i.e., negative versus positive emotions). The two appraisals are differentiated based on expected outcomes of a behavior. Namely, threat is expected to lead to negative outcomes, and challenge is expected to lead to mastery and gain. In the original discussion of these two appraisals, Lazarus and Folkman (1984) noted that threat and challenge appraisals are not mutually exclusive and should not be viewed as the opposites of a single continuum (Lazarus & Folkman, 1984). Although these appraisals are related, they should be measured separately.

Following prior research (Mishel et al., 2005; Rains & Tukachinsky, 2015) and the original conceptualization, this study measured uncertainty appraisal using a scale that includes both cognitive and affective evaluation of threat and challenge. After completing the information-seeking portion of the survey, participants were asked to rate the degree to which they felt a series of emotions when they thought about participation in a clinical research study. Cognitive threat evaluation included three items that assess the extent to which participation in a clinical research study is perceived as threatening, implying negative consequences, and leading to losses. The items are listed below.

- Participation in the advertised clinical study represents a threat to me
- If I participate in the advertised clinical study, it will have negative consequences
- My participation in the advertised clinical study can lead to losses for me

Cognitive challenge evaluation included six items that assess the extent to which participation in a clinical study is viewed as challenging, providing an opportunity for personal growth, and leading to positive outcomes. The items are listed below.

- Participation in the advertised clinical study represents a threat to me
- If I participate in the advertised clinical study, it will have negative consequences
- My participation in the advertised clinical study can lead to losses for me
- Challenge in the advertised clinical study provides an opportunity for personal growth
- Challenge in the advertised clinical study leads to positive outcomes
- Challenge in the advertised clinical study provides an opportunity for personal development
Participation in the advertised clinical study can be beneficial to me. If I participate in the advertised clinical study, it can lead to positive outcomes. Participation in the advertised clinical study provides an opportunity to contribute to the society. My participation in the advertised study can lead to important discoveries. Participation in the advertised study can make a difference. My participation in the advertised clinical study can inspire others.

To evaluate the affective component of uncertainty appraisal, participants were asked to assess how the thought of participating in the advertised clinical study made them feel. Threat emotions include fear, anxiousness, and worry (Lazarus & Folkman, 1984; Rains, 2014), and challenge emotions include eagerness, hopefulness, and confidence.

- When I think about the advertised clinical study, it makes me feel worried.
- I feel fearful when I think about the advertised clinical study.
- The advertised clinical study makes me feel anxious.

- When I think about the advertised clinical study, it makes me feel eager.
- I feel confident when I think about the advertised clinical study.
- The advertised clinical study makes me feel hopeful.

All uncertainty appraisal items were measured using a 7-point scale with anchors “very strongly disagree” and “very strongly agree.”

**Observed information behavior**

UMT views communicative behavior as a core activity in uncertainty management (Brashers, 2001) with information seeking being one of the most frequent types of such behavior. Information behavior was measured through objective page-use data collected through unobtrusive Qualtrics survey meta-data and a participant self-report measure.

Participants were provided with an opportunity to read up to seven short messages about three topics: clinical trial research, cancer, and daily use of aspirin. Previous research on online information seeking focused on the total number of pagers.
accessed and average time per page (Rains & Tukachinsky, 2015) or time per page given selective exposure to information (Knobloch-Westerwick & Sarge, 2015). However, understanding information behavior relative to several possible information topics still calls for more research and methodological development (Rains & Tukachinsky, 2015). The measurement of the information behavior related to several topics is challenged by the fact that a combined average page access provides incomplete presentation of the data variability. For example, an average of visited pages for a participant who accessed two questions for each of the three topics or six questions for one topic would be the same; yet, these information behaviors are distinctly different.

**Self-reported information behavior**

In addition to the self-reported information behavior, a 4-item 7-point scale adapted from HINTS (HINTS, 2014) was used to collect self-reported data about participant information behavior. Participants were asked to express their disagreement (1) or agreement (7) with the following four statements:

- I looked for information about clinical studies.
- I looked for information about general health topics.
- I wanted to avoid information about clinical studies.
- I did not look for information on any particular topic.

**Dependent Variable**

Behavioral intention is the primary dependent variable for this study. A comprehensive meta-analysis looked at the measurement of behavioral intention (BI) and identified that BI can be measured as desire (‘I want to perform behavior x’), self-prediction (‘I will perform behavior x’), or intention (‘I intend to perform behavior x’) (Armitage & Conner, 2001). Among these measures, intention was identified as the
strongest. Additional methodological research has labeled these measures as goal intention, which is different from implementation intention (Gollwitzer & Brandstätter, 1997; Milne, Orbell, & Sheeran, 2002). The latter may include specifics in terms of how, when, and what behavioral actions might take place.

BI for the present study was measured using a 2-item 7-point scale to indicate a combination of a goal and implementation intention items. Participants were asked to what extent they disagree (1) or agree (7) with the following statements:

- I plan to leave my contact information to be contacted about the advertised research study
- I intend to participate in the advertised research study

**Data Analysis**

Several hypotheses and research questions evaluated in this dissertation focused on mediation and moderation analysis. Moderation analysis evaluates how an independent variable affects a dependent variable based on its relationship with a third variable (Baron & Kenny, 1986). Moderation evaluated when or under which conditions an independent variable directly influences a dependent variable (Preacher & Hayes, 2008). In contrast, mediation analysis is concerned with a sequence of causal relationships between variables and tests to evaluate how, or through which pathway, an independent variable predicts a dependent variable (Hayes, 2013). Confirming the total effect of an independent variable on a dependent variable, mediation should also show a significant indirect effect of an independent variable on a dependent variable through one or more mediators. Furthermore, if an independent variable has no direct effect on a dependent variable, the relationship constitutes a case of complete mediation (Baron & Kenny, 1986; Hayes, 2013).
Several forms of moderation have been utilized in behavioral and social science literature, including Baron and Kenny’s framework (Baron & Kenny, 1986) or Sobel’s test (Preacher & Hayes, 2008). However, bootstrapping is currently the most supported form of moderation and mediation analysis (Hayes, 2009, 2013). Bootstrapping is a resampling technique that involves random sampling with replacement and does not require assumptions of normality in variable distribution, thus overcoming difficulties with non-normally distributed variables. To conduct the analyses of moderation and mediation relationships suggested by the hypotheses in this dissertation, the PROCESS computational tool was selected. PROCESS is an SPSS macro that uses regression analyses with bootstrapping and provides a user-friendly interface for the testing of moderation, mediation, and serial mediation analyses with up to ten covariates (Hayes, 2013). All results using PROCESS reported in this dissertation were based on 5,000 bootstrapping resampling analyses. Next, specific tests that were used to test hypotheses and research questions will be briefly described.

H1 predicted that information-seeking self-efficacy would moderate uncertainty appraisal resulting from decisional conflict related to participation in clinical research. A conceptual model of the relationships between an independent variable X, decisional conflict, a moderator M, information-seeking self-efficacy, and a dependent variable Y, uncertainty appraisal, is shown in Figure 3-2. The PROCESS macro (model 1) was used to test the hypothesis.
H2 suggested that uncertainty appraisal predicts information behavior. Multiple regression analyses were used to test this hypothesis and assess if threat and challenge appraisals predict self-reported information seeking and information avoidance. Similar multiple regression tests were used to assess if threat and challenge appraisals predict observable information behavior measured as number of information topics read and time spent per topic.

H3 predicted that information-seeking self-efficacy would moderate the relationship between uncertainty appraisal and information behavior. Similar to H1, a moderation analysis using PROCESS macro was used.

H4 predicted that need for cognition would affect the appraisal-information seeking relationship. A three-block hierarchical logistic regression was used to test whether information-seeking self-efficacy, uncertainty appraisal, and need for cognition variables predict information behavior. Two separate models were tested, one for predicting information seeking and one for information avoidance.

H5 suggested that probabilistic and evaluative uncertainty predict decisional conflict related to participation in clinical research, and that the two forms of uncertainty would interact. The PROCESS moderation model (model 1) was used to assess both
the direct effects of probabilistic and evaluative uncertainty on decisional conflict and the interaction between the two forms of uncertainty.

H6 predicted that trust in medical researchers affects the relationship between race and information behavior. The PROCESS (model 74) was used to assess the role of trust in race and information behavior. Serial mediation testing allows evaluating race as a predictor of trust in medical researchers, race as a predictor of information seeking, and the interaction between race and trust in medical researcher as a predictor of information seeking. Figure 3-3 shows a graphical representation of the model.

H7 predicted that race affects information behavior. An analysis of variance (ANOVA) test was used to evaluate the differences in information behavior between Caucasians \( n = 170 \), coded as a 0) and African Americans \( n = 170 \), coded is a 1).

H8 suggested that trust in medical researchers and information-seeking self-efficacy form a serial mediation model that explains the effect of race on information behavior and behavioral intention to participate in clinical research. The PROCESS macro (model 6) allows assessing mediation models with up to four mediators operating in series. The first model tested the effect of race on information behavior mediated by trust in medical researchers and information-seeking self-efficacy. Figure 3-4 shows the model and relationships for two mediators. Subsequently, a second model evaluated
the effect of race mediated by trust in medical researchers, information-seeking self-efficacy, and information behavior on behavioral intention to participate in clinical research. Figure 3-5 shows the model and relationships for three mediators.

Figure 3-4. Serial mediation model with two mediators.

Figure 3-5. Serial mediation model with three mediators.

H9 suggested that decisional conflict, uncertainty appraisal, and information behavior would predict behavioral intention to participate in clinical research. The PROCESS macro was used to test two serial mediation models, one with information seeking as one of the mediators and another with information avoidance as one of the mediators. Conceptual representation of the tested model is similar to the one previously presented in Figure 3-5.
RQ1 sought to explore the differences in the information behavior and content that attracts attention among health consumers who experience probabilistic uncertainty related to randomization or evaluative uncertainty related to cancer risk information. A Pearson’s correlation was used to determine the associations between probabilistic and evaluative uncertainty and information behavior.

RQ2 asked about the differences in uncertainty appraisal related to participation in a clinical research study between males and females. An analysis of variance was done to assess the differences cognitive and affective appraisal of uncertainty.

RQ3 asked about the extent to which gender is a predictor of the appraisal-information seeking relationship. To answer RQ3 and evaluate the role of gender as a predictor in the relationship, two hierarchical regression models were assessed, one examining information seeking and another examining information avoidance as the dependent variables.

For regression-based analyses, unstandardized beta coefficients (b) are reported for PROCESS-based mediation and moderation models, and standardized beta coefficients (β) are reported for multiple regression models.

**Power Analysis**

This study proposed a factorial experiment with 2 (present/absent probabilistic uncertainty) x 2 (present/absent evaluative uncertainty) x 2 (high/low self-efficacy) conditions. Following directions for power considerations for factorial designs (Collins, Dziak, Kugler, & Trail, 2014), the sample size was estimated based on the lowest power of the tested factors. Experimental data using situational uncertainty about occurrence or non-occurrence of an event as an independent variable for information seeking showed a medium effect size, Cohen’s $d = 0.71$ (Rosen & Knäuper, 2009) High/low
uncertainty related to the evaluation of an event as positive or negative (operationalized as threat) showed a large effect size, Cohen’s $d = 0.91$ (Witte & Allen, 2000).

Self-efficacy to cope with uncertainty was operationalized as an uncertainty and information management skill for this study. In the context of patient communication training, several approaches for health information efficacy have been identified. Training could include provision of essential, core questions relevant to a particular health context, assistance with formulating additional questions of particular concern to patients, setting goals for information seeking, and provision of a list of sample questions (Cegala et al., 2001). To tailor the list of sample questions to the individual needs of patients, patients could be provided with an option to select relevant questions, and combine them to create their own lists (Cegala et al., 2001). A number of successful patient communication skill interventions were developed and delivered to general audiences (Cegala et al., 2000) and older adults (Cegala et al., 2001). Original interventions included face-to-face training and home-based self-training (Cegala et al., 2000). Later iterations also added a written brochure as an additional mechanism for patients to develop and practice question-asking. The brochure guided patients through communication skill development, i.e. the independent formulation of questions, establishment of information-seeking goals, and selection of personally relevant questions from a suggested list (Cegala et al., 2001). Effect size for the written communication skills intervention compared to an invitation to ask questions that is not supported by communication skills training is 0.54 measured by Cohen's $d$ (Cegala et al., 2000).
To detect an effect with an $\alpha = 0.01$, a power of 0.80 (two-tailed t-test), a sample size is estimated at $N = 164$. However, because experimental manipulation of probabilistic and evaluative orientations has not been done before, the calculated sample size was doubled for a target sample of $N = 328$.

**Scale Analyses**

To examine the potential for items to be combined into composite scales, they were first examined for face validity to see if the items appeared to measure the same construct. Then, the reliability of the scales was assessed using Cronbach's alpha. Cronbach's alpha and mean ($M$) values for each scale are reported in Table 3-2.

<table>
<thead>
<tr>
<th>Scale Name</th>
<th>Cronbach's alpha</th>
<th>$M$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Trust in medical researchers</td>
<td>.87</td>
<td>4.29</td>
</tr>
<tr>
<td>Need for cognition</td>
<td>.84</td>
<td>4.48</td>
</tr>
<tr>
<td>Decision-making autonomy</td>
<td>.83</td>
<td>5.78</td>
</tr>
<tr>
<td>Information-seeking self-efficacy (eHEALS)</td>
<td>.92</td>
<td>5.11</td>
</tr>
<tr>
<td>Probabilistic uncertainty</td>
<td>.90</td>
<td>4.46</td>
</tr>
<tr>
<td>Evaluative uncertainty</td>
<td>.90</td>
<td>5.14</td>
</tr>
<tr>
<td>Decisional conflict</td>
<td>.88</td>
<td>2.31</td>
</tr>
<tr>
<td>Cognitive threat appraisal</td>
<td>.90</td>
<td>2.93</td>
</tr>
<tr>
<td>Cognitive challenge appraisal</td>
<td>.93</td>
<td>5.68</td>
</tr>
<tr>
<td>Affective threat appraisal</td>
<td>.88</td>
<td>3.59</td>
</tr>
<tr>
<td>Affective challenge appraisal</td>
<td>.83</td>
<td>4.86</td>
</tr>
<tr>
<td>Combined threat appraisal</td>
<td>.89</td>
<td>3.26</td>
</tr>
<tr>
<td>Combined challenge appraisal</td>
<td>.91</td>
<td>5.40</td>
</tr>
<tr>
<td>Behavioral intention</td>
<td>.89</td>
<td>4.81</td>
</tr>
</tbody>
</table>

**Item Analyses**

Although the use of the PROCESS macro for SPSS allows the inclusion of non-normally distributed variables in the analysis, all the items were examined for normality. Skew and kurtosis were examined by dividing the skew and kurtosis statistics by their standard errors to obtain a t-statistic. The criteria of $p < .01$ ($t > 2.58$) was applied to
identify items that were statistically significantly skewed or kurtotic (Tabachnick & Fidell, 2007). For the observed information seeking, the number of topics accessed, $t(339) = 5.69$, and time per topic, $t(339) = 34.01$, variables were highly positively skewed. After logarithmic (log 10) transformation, both number of topics accessed, $t(339) = -2.50$, and time per topic, $t(339) = -2.01$, showed acceptable levels of skewness.
CHAPTER 4
RESULTS

Sample

Data for the experiment were collected from an equal-size strata through a consumer research company, Survey Sampling International (SSI). The final sample consisted of 340 participants (170 male, 170 female; 170 Caucasian, 170 African American). The age of participants ranged from 18 to 83 ($M = 41.57$, $SD = 15.82$). Twenty-two participants (6.5%) indicated their ethnicity as “Hispanic or Latino.” Participants’ levels of education included less than high school ($n = 4$, 1.2%), high school/GED ($n = 55$, 16.2%), some college ($n = 100$, 29.4%), college graduate ($n = 130$, 38.2%), and post-graduate ($n = 51$, 15.0%); levels of income included less than $20,000 ($n = 55$, 16.2%), $20,000-$49,999 ($n = 114$, 33.5%), $50,000-$99,999 ($n = 113$, 33.2%), and $100,000 or more ($n = 49$, 14.4%). Nine participants (2.6%) chose not to disclose their level of income. Reporting about their health status, eight (2.4%) participants self-assessed it as “poor,” 65 (19.1%) self-assessed it as “fair,” 132 (38.8%) self-assessed it as “good,” 101 (29.7%) self-assessed it as “very good,” and 34 (10.0%) self-assessed it as “excellent.” Demographic characteristics of the study sample are summarized in Table 4-1.

Independent Variable Manipulation Checks

Manipulation checks were conducted on each of the two independent variables: information seeking self-efficacy and uncertainty about participation in clinical research. As described below, the ANOVAs for both manipulation checks all found the expected main effects and confirmed successful manipulation of conditions.
Table 4-1. Demographic characteristics of the study sample

<table>
<thead>
<tr>
<th>Variable</th>
<th>Values</th>
<th>N (%)</th>
<th>M (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>Male</td>
<td>170 (50)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>170 (50)</td>
<td></td>
</tr>
<tr>
<td>Race</td>
<td>Caucasian</td>
<td>170 (50)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>African American</td>
<td>170 (50)</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>Min: 18, Max: 83</td>
<td></td>
<td>41.57 (15.28)</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>Non-Hispanic</td>
<td>318 (93.5)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Hispanic</td>
<td>22 (6.5)</td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td>Less than high school</td>
<td>4 (1.2)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>High school/GED</td>
<td>55 (16.2)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Some college</td>
<td>100 (29.4)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>College graduate</td>
<td>130 (38.2)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Post-graduate</td>
<td>51 (15.0)</td>
<td></td>
</tr>
<tr>
<td>Income</td>
<td>Less than $20,000</td>
<td>55 (16.2)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>$20,000-$49,999</td>
<td>114 (33.5)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>50,000-99,999</td>
<td>113 (33.2)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>$100,000 or more</td>
<td>49 (14.4)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>No response</td>
<td>9 (2.6)</td>
<td></td>
</tr>
<tr>
<td>Family Status</td>
<td>Married</td>
<td>157 (46.2)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Separated</td>
<td>6 (1.8)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Divorced</td>
<td>36 (10.6)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Widowed</td>
<td>7 (2.1)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Never been married</td>
<td>134 (39.4)</td>
<td></td>
</tr>
<tr>
<td>Health Status</td>
<td>Min: 1, Max: 5</td>
<td></td>
<td>3.26 (.96)</td>
</tr>
<tr>
<td>Personal History of Cancer</td>
<td>No</td>
<td>328 (96.5)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>12 (3.5)</td>
<td></td>
</tr>
</tbody>
</table>

**Information-seeking Self-efficacy**

The information-seeking self-efficacy manipulation check was conducted immediately after participants read a short message about benefits/challenges of online information seeking and selected the benefits/challenges they felt were most relevant and applicable to them from a list of 15 items. The ANOVA revealed the expected simple main effect of manipulated self-efficacy level (high and low) on participants' self-
efficacy for online information seeking, \( F(1, 338) = 8.80, p < .003, \eta = .03 \). The review of means showed that participants who read about and selected benefits of online information seeking perceived themselves to be better able to look for information online \( (n = 167, M = 5.29, SD = 1.03) \) than were subjects who received the information about the challenges of online information seeking \( (n = 173, M = 4.93, SD = 1.18) \). Analyses of self-efficacy levels among demographic variables (gender, race, age, income, education, and age) were not statistically significant, which confirms that the experimental manipulation was successful.

**Uncertainty Related to Participation in Clinical Research**

Four recruitment message stimuli were manipulated to include low/high probabilistic/evaluative uncertainty. The uncertainty related to participation in clinical research manipulation check was conducted immediately after participants read a recruitment message inviting them to participate in a research study. An ANOVA revealed the expected effect of manipulated level of probabilistic and evaluative uncertainty. For probabilistic uncertainty, data for the no uncertainty condition \( (n = 91, M = 3.45, SD = 1.70) \) showed expected significant differences, \( F(3, 336) = 63.15, p < .001 \), compared to the probabilistic uncertainty condition \( (n = 83, M = 5.63, SD = 1.12) \) and probabilistic and evaluative uncertainty \( (n = 80, M = 5.67, SD = 1.11) \) conditions. Similarly, the no uncertainty condition \( (n = 91, M = 4.92, SD = 1.43) \) showed expected significant differences, \( F(3, 336) = 3.56, p < .02 \), compared to the evaluative uncertainty condition \( (n = 86, M = 5.39, SD = .94) \) and the probabilistic and evaluative uncertainty \( (n = 80, M = 5.35, SD = 1.06) \) conditions. Analyses of variances of time spent viewing recruitment message, perceived readability level, perceive trust level, and reported level of yielding did not show any significant differences among conditions.
Hypothesis Testing

Hypothesis 1

Hypothesis 1 predicted that information-seeking self-efficacy would moderate uncertainty appraisal. Specifically, it suggested that health consumers with high information-seeking self-efficacy would evaluate the uncertainty associated with prospective study participation as a challenge (H1a), and that health consumers with low information-seeking self-efficacy would evaluate the uncertainty associated with prospective study participation as a threat (H1b). Table 4-21 provides the means, standard deviations, and bivariate correlations for the information-seeking self-efficacy and uncertainty appraisal variables.

Table 4-2. Means, standard deviations, and bivariate correlations for the information-seeking self-efficacy and uncertainty appraisal variables

<table>
<thead>
<tr>
<th></th>
<th>M</th>
<th>SD</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-efficacy (1)</td>
<td>5.11</td>
<td>1.12</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cognitive threat appraisal (2)</td>
<td>2.93</td>
<td>1.59</td>
<td>.021</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cognitive challenge appraisal (3)</td>
<td>5.67</td>
<td>.99</td>
<td>.267**</td>
<td>-.322**</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Affective threat appraisal (4)</td>
<td>3.59</td>
<td>1.58</td>
<td>-.035</td>
<td>.592**</td>
<td>-.204**</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Affective challenge appraisal (5)</td>
<td>4.86</td>
<td>1.22</td>
<td>.314**</td>
<td>-.180**</td>
<td>.595**</td>
<td>-.132’</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Threat appraisal index (6)</td>
<td>3.26</td>
<td>1.41</td>
<td>-.007</td>
<td>.893**</td>
<td>-.295**</td>
<td>.891**</td>
<td>-.175”</td>
<td></td>
</tr>
<tr>
<td>Challenge appraisal index (7)</td>
<td>5.27</td>
<td>.99</td>
<td>.327**</td>
<td>-.272**</td>
<td>.867**</td>
<td>-.184”</td>
<td>.916”</td>
<td>-.256**</td>
</tr>
</tbody>
</table>

** Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

PROCESS Model 1 was used to test the moderation effect of information-seeking self-efficacy on the relationship between probabilistic and evaluative uncertainty and threat and challenge uncertainty appraisal. Four separate models were tested.
To test hypothesis 1a, that uncertainty is moderated by self-efficacy in predicting challenge appraisal, a moderation analysis was conducted with probabilistic uncertainty and evaluative uncertainty as independent variables, information-seeking self-efficacy as a moderator, and challenge appraisal as dependent variable. The overall model with probabilistic uncertainty as the independent variable was significant, \( F(3, 336) = 12.59, \ p < .01, \ R^2 = .12 \). The model did not show a main effect of probabilistic uncertainty, \( b = - .01, \ t(336) = - .24, \ p = .81 \) (also depicted in Figure 4-1), but both information-seeking self-efficacy, \( b = .30, \ t(336) = 5.52, \ p < .01 \), and the interaction between probabilistic uncertainty and information-seeking self-efficacy, \( b = .06, \ t(336) = 2.22, \ p < .03 \), were significant predictors. \( R^2 \) change due to the interaction was .02 and was significant, \( F(1, 336) = 4.93, \ p < .03 \).

![Figure 4-1. A model of the effect of probabilistic uncertainty on challenge appraisal moderated by information-seeking self-efficacy.](image)

The overall model with evaluative uncertainty as the independent variable was significant, \( F(3, 336) = 14.48, \ p < .01, \ R^2 = .12 \). The model did not show the main effect of evaluative uncertainty, \( b = .09, \ t(336) = 1.77, \ p = .08 \). Information-seeking self-efficacy, \( b = .26, \ t(336) = 4.38, \ p < .01 \), was a significant predictor of opportunity appraisal, but the interaction between evaluative uncertainty and information-seeking
self-efficacy, $b = .05$, $t(336) = .78$, $p = .44$, was not supported; see figure 4-2. Hypothesis 1a was not supported.

Figure 4-2. A model of the effect of evaluative uncertainty on challenge appraisal moderated by information-seeking self-efficacy.

To test hypothesis 1b, that uncertainty appraisal is moderated by self-efficacy in predicting threat appraisal, a moderation analysis using PROCESS Model 1 was conducted with probabilistic uncertainty and evaluative uncertainty as independent variables, information-seeking self-efficacy as a moderator, and threat appraisal as a dependent variable. The overall model with probabilistic uncertainty as the independent variable was significant, $F(3, 336) = 9.61$, $p < .01$, $R^2 = .08$. The model showed a main effect of probabilistic uncertainty, $b = .20$, $t(336) = 4.89$, $p < .01$, but neither information-seeking self-efficacy, $b = -.06$, $t(336) = -.92$, $p = .36$, nor the interaction between probabilistic uncertainty and information-seeking self-efficacy, $b = .05$, $t(336) = 1.31$, $p = .19$, were significant predictors; see Figure 4-3.
The overall model with evaluative uncertainty as the independent variable was significant, $F(3, 336) = 12.14, p < .01, R^2 = .09$. The model showed the main effect of evaluative uncertainty, $b = .32, t(336) = 5.52, p < .01$, but neither information-seeking self-efficacy, $b = -.08, t(336) = -1.11, p = .27$, nor the interaction between probabilistic uncertainty and information-seeking self-efficacy, $b = .04, t(336) = .68, p = .50$, were significant predictors. Hypothesis 1b was not supported.
Hypothesis 2

Hypothesis 2 suggested that uncertainty appraisal would predict information behavior (H2a). Specifically, it predicted that threat appraisal would result in health information consumers accessing more topics (H2b) and spending less time per topic (H2c) than challenge appraisal. Two multiple regression models predicting information behavior were evaluated using threat and challenge appraisals as predictors.

For the first regression, self-reported information seeking was the dependent variable, and for the second regression, self-reported information avoidance was the dependent variable. The information seeking regression was significant, $F(2, 337) = 34.26, p < .001$, $R^2 = .17$. The model identified challenge appraisal as a significant predictor, $\beta = .42, t(337) = 8.15, p < .001$, but threat appraisal was not significant, $\beta = .04, t(337) = .70, p = .49$. The information avoidance regression model was significant, $F(2, 337) = 41.88, p < .001$, $R^2 = .20$. The model identified threat appraisal as a significant predictor, $\beta = .46, t(337) = 9.07, p < .001$, but challenge appraisal was not significant, $\beta = .06, t(337) = .70, p = .23$.

Table 4-3. The role of threat and challenge appraisal of uncertainty as predictors of information avoidance.

<table>
<thead>
<tr>
<th>Predictor variable</th>
<th>Information seeking</th>
<th>Information avoidance</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$\beta(\text{SE})$</td>
<td>$R^2$</td>
</tr>
<tr>
<td>Threat appraisal</td>
<td>.04 (.06)</td>
<td>.17</td>
</tr>
<tr>
<td>Challenge appraisal</td>
<td>.42 (.08)***</td>
<td></td>
</tr>
</tbody>
</table>

* $p < .05$; ** $p < .01$; *** $p < .001$

These findings support the general role of uncertainty appraisal as a predictor of information behavior and support H2a. They also suggest that information seeking and
information avoidance are discrete behaviors that are predicted by different types of uncertainty appraisal. These findings will be further addressed in the Discussion section.

Two stepwise multiple regression models were used to evaluate threat and challenge appraisals as predictors of observable information seeking behavior. For the first regression, number of pages visited was the dependent variable, and for the second regression, time spent per page was the dependent variable. The page visit regression was significant, $F(2, 337) = 14.57, p < .01, R^2 = .04$. The model identified threat appraisal as a significant predictor, $\beta = -1.93, t(337) = -3.50, p < .01$, but challenge appraisal was not significant, $\beta = .04, t(337) = .73, p = .47$. The time spent regression model was significant, $F(2, 337) = 4.36, p < .05, R^2 = .01$. The model identified threat appraisal as a significant predictor, $\beta = -.12, t(337) = -2.513, p < .05$, but challenge appraisal was not significant, $\beta = -.03, t(337) = -.44, p = .66$. The results of these data analyses showed that threat appraisal results in fewer visited pages and less time spent per page. Therefore, H2b was not supported, and H2c was supported.

**Hypothesis 3**

Hypothesis 3 predicted that information-seeking self-efficacy would affect the relationship between uncertainty appraisal and information behavior (H3a). Specifically, it suggested that health consumers with high information-seeking self-efficacy who appraise uncertainty about participation in a clinical study as a threat would spend more time on topics they visit than those with low self-efficacy (H3b). Furthermore, health consumers with high information-seeking self-efficacy who appraise uncertainty about participation in a clinical study as challenge were expected to engage with more topics than those with low self-efficacy (H3c).
First, four moderation models were evaluated to assess the relationship between uncertainty appraisal, information-seeking self-efficacy, and self-reported information behavior. The overall model with threat appraisal as the independent variable and information seeking as the dependent variable was significant, $F(3, 336) = 12.32, p < .01, R^2 = .11$. The model did not show a main effect of threat appraisal, $b = -.10, t(336) = -1.63, p = .10$. Information-seeking self-efficacy, $b = .42, t(336) = 5.42, p < .01$, and the interaction between threat appraisal and information-seeking self-efficacy, $b = .12, t(336) = 2.59, p < .01$, were both significant predictors of information seeking. $R^2$ change due to interaction was .02 and was significant, $F(1, 336) = 6.70, p < .01$; see Figure 4-5.

![Diagram of moderation model](attachment:moderation_model.png)

*Figure 4-5. A model of the effect of threat appraisal on information seeking moderated by information-seeking self-efficacy.*

The overall model with challenge appraisal as the independent variable and information seeking as the dependent variable was significant, $F(3, 336) = 34.59, p < .01, R^2 = .20$. The model showed significant main effects of challenge appraisal, $b = .56, t(336) = 5.88, p < .01$, and information-seeking self-efficacy, $b = .24, t(336) = 2.57, p < .01$. However, the interaction between challenge appraisal and information-seeking self-efficacy, $b = .08, t(336) = .95, p = .34$, was not significant; see Figure 4-6.
Figure 4-6. A model of the effect of challenge appraisal on information seeking moderated by information-seeking self-efficacy.

The overall model with threat appraisal as the independent variable and information avoidance as the dependent variable was significant, $F(3, 336) = 27.17, p < .01, R^2 = .21$. The model showed significant main effects of threat appraisal, $b = .58$, $t(336) = 8.54, p < .01$, and information-seeking self-efficacy, $b = .20$, $t(336) = 2.43, p < .05$. However, the interaction between threat appraisal and information-seeking self-efficacy, $b = .06$, $t(336) = 1.16, p = .25$, was not significant; see Figure 4-7.

Figure 4-7. A model of the effect of threat appraisal on information avoidance moderated by information-seeking self-efficacy.

The overall model with challenge appraisal as the independent variable and information avoidance as the dependent variable was significant, $F(3, 336) = 3.33, p <$
The model showed a significant main effect of information-seeking self-efficacy, $b = .24$, $t(336) = 2.65$, $p < .01$. However, neither challenge appraisal, $b = -.20$, $t(336) = -1.78$, $p = .08$, nor the interaction between challenge appraisal and information-seeking self-efficacy, $b = .03$, $t(336) = .39$, $p = .70$, were significant; see Figure 4-8.

Figure 4-8. A model of the effect of challenge appraisal on information avoidance moderated by information-seeking self-efficacy.

H3a was supported. These tests confirm that information-seeking self-efficacy affects information behavior. The data showed that information-seeking self-efficacy is a significant direct predictor for both information seeking and information avoidance. However, the interaction of information-seeking self-efficacy and uncertainty appraisal was significant only for threat appraisal but not for the challenge appraisal. Although threat appraisal is not a significant predictor for information seeking, the data showed that interacting with information-seeking self-efficacy, it led to lower levels of information seeking for those with low information-seeking self-efficacy and greater information seeking for those with high information-seeking self-efficacy. See Figure 4-9.
Two moderation models were assessed to evaluate the effect of information-seeking self-efficacy on the relationship between threat and observed information seeking. The first model with threat appraisal as the independent variable and time per page as dependent variable was not significant, $F(3, 336) = 1.47$, $p = .22$, $R^2 = .01$. The second model evaluated challenge appraisal as the independent variable and number of pages visited as the dependent variable. Although the direct effect of challenge appraisal was significant, $b = .03$, $t(336) = 2.03$, $p < .05$, and the direct effect of
information-seeking self-efficacy approached significance, \( b = -.03, t(336) = -1.76, p = .08 \), neither the interaction, \( b = -.01, t(336) = -.58, p = .56 \), nor the overall model were significant, \( F(3, 336) = 1.73, p = .16, R^2 = .02 \). Therefore, H3b and H3c were not supported.

**Hypothesis 4**

Hypothesis 4 predicted that need for cognition would affect the relationship between appraisal and information seeking. A three-block hierarchical logistic regression was used to test whether information-seeking self-efficacy, uncertainty appraisal, and need for cognition variables predict information behavior. Two separate models were tested, one for predicting information seeking and one for information avoidance. Information-seeking self-efficacy was entered in the first block, threat and challenge evaluation were entered in the second block, and need for cognition was entered in the third block.

The first model predicted information seeking. The first block with information-seeking self-efficacy was significant and accounted for 9% of the variance, \( F(1, 338) = 32.60, p < .01, R^2 = .09 \). In the second block, threat and opportunity appraisals were added. Together, they accounted for 19%, \( F(3, 336) = 27.61, p < .01, R^2 = .19 \). Finally, need for cognition was added. The final model accounted for 22% and was significant, \( F(4, 335) = 23.27, p < .01, R^2 = .21 \). Standardized beta scores and standard errors for all three steps of the model are shown in Table 4-4.

The second model used information avoidance as the dependent variable. The first block with information-seeking self-efficacy was significant and accounted for 1%, \( F(1, 338) = 4.60, p < .05, R^2 = .01 \). In the second block, threat and opportunity appraisals were added. Together, they accounted for 21%, \( F(3, 336) = 29.78, p < .01, \)
Finally, need for cognition was added. The final model accounted for 22% and was significant, $F(4, 335) = 23.41, p < .01, R^2 = .22$. Standardized beta scores and standard errors for all three steps of the model are shown in Table 4-5.

Table 4-4. The role of need for cognition on information seeking.

<table>
<thead>
<tr>
<th>Predictor variable</th>
<th>β(SE)</th>
<th>95% CI</th>
<th>$R^2$</th>
<th>$\Delta R^2$</th>
<th>$F$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information-seeking self-efficacy</td>
<td>.42 (.07)**</td>
<td>[.28, .56]</td>
<td>.088</td>
<td></td>
<td>32.60***</td>
</tr>
<tr>
<td>Step 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information-seeking self-efficacy</td>
<td>.26 (.07)**</td>
<td>[.11, .40]</td>
<td>.198</td>
<td>.11</td>
<td>27.61***</td>
</tr>
<tr>
<td>Threat appraisal</td>
<td>.02 (.06)</td>
<td>[-.09, .14]</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Challenge appraisal</td>
<td>.57 (.09)**</td>
<td>[.40, .72]</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Step 3</td>
<td>.217</td>
<td>.02</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information-seeking self-efficacy</td>
<td>.25 (.07)**</td>
<td>[.11, .40]</td>
<td>.217</td>
<td>.02</td>
<td>23.27***</td>
</tr>
<tr>
<td>Threat appraisal</td>
<td>.55 (.09)</td>
<td>[-.09, .14]</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Challenge appraisal</td>
<td>.07 (.06)**</td>
<td>[.40, .72]</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Need for cognition</td>
<td>.28 (.10)**</td>
<td>[.09, .48]</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* $p < .05$; ** $p < .01$; *** $p < .001$

Table 4-5. The role of need for cognition on information avoidance.

<table>
<thead>
<tr>
<th>Predictor variable</th>
<th>β(SE)</th>
<th>95% CI</th>
<th>$R^2$</th>
<th>$\Delta R^2$</th>
<th>$F$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information-seeking self-efficacy</td>
<td>.19 (.09)*</td>
<td>[.15, .37]</td>
<td>.013</td>
<td></td>
<td>4.60*</td>
</tr>
<tr>
<td>Step 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information-seeking self-efficacy</td>
<td>.16 (.09)*</td>
<td>[.02, .35]</td>
<td>.210</td>
<td>.12</td>
<td>29.78***</td>
</tr>
<tr>
<td>Threat appraisal</td>
<td>.60 (.07)**</td>
<td>[.46, .72]</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Challenge appraisal</td>
<td>.04 (.10)</td>
<td>[-.16, .24]</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Step 3</td>
<td>.218</td>
<td>.01</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information-seeking self-efficacy</td>
<td>.25 (.07)*</td>
<td>[.11, .40]</td>
<td>.218</td>
<td>.01</td>
<td>23.41***</td>
</tr>
<tr>
<td>Threat appraisal</td>
<td>.56 (.07)**</td>
<td>[.42, .69]</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Challenge appraisal</td>
<td>.06 (.10)</td>
<td>[-.13, .26]</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Need for cognition</td>
<td>-.22 (.12)*</td>
<td>[-.45, .01]</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* $p < .05$; ** $p < .01$; *** $p < .001$; # $p = .06$
The results of the data analyses showed that need for cognition is a significant predictor of information seeking, $\beta = .28$, $t(335) = 2.90$, $p < .01$, but did not reach significance as a predictor of information avoidance, $\beta = -.22$, $t(335) = -1.90$, $p = .06$. Standardized beta scores suggest that higher need for cognition results in greater information seeking. At the same time, lower need for cognition could result in greater information avoidance. H4 was partially supported.

**Hypothesis 5**

Hypothesis 5 predicted that probabilistic and evaluative uncertainty would show chaining effects. Specifically, the presence of probabilistic uncertainty related to randomization (H5a) and the presence of evaluative uncertainty related to cancer risk information (H5b) were expected to result in decisional conflict related to participation in clinical research. Evaluative and probabilistic uncertainty were also expected to interact thus explaining decisional conflict about participation in clinical research (H5c).

A hierarchical regression model was evaluated to assess whether probabilistic and evaluative uncertainty predict decisional conflict about participation in clinical research independently, and if the two variables interact. The model was entered in two blocks. First, probabilistic and evaluative uncertainty were entered and resulted in a significant model, $F(2, 337) = 4.03$, $p < .02$, $R^2 = .02$. Next, an interaction term of probabilistic and evaluative uncertainty was entered and also resulted in a significant model, $F(3, 336) = 4.11$, $p < .01$, $R^2 = .04$. The review of the beta coefficients revealed that probabilistic uncertainty is not a significant predictor, $t(337) = -.51$, $\beta = -.02$, $p = .61$, while evaluative uncertainty is a significant predictor, $t(337) = -2.71$, $\beta = -.19$, $p < .01$, of decisional conflict related to participation in clinical research. Therefore, H5a was not supported, and H5b was supported.
The review of the beta coefficient for the interaction term revealed a significant effect, $t(336) = -2.05, \beta = -.51, p < .05$. The direction of the beta coefficient suggests that the interaction of probabilistic and evaluative uncertainty decreases uncertainty related to participation in clinical research. H5c was, therefore, supported.

**Hypothesis 6**

Hypothesis 6 predicted that trust in medical researchers affects the relationship between race and information behavior. PROCESS Model 74 was used to assess the role of trust in the relationship between race and information behavior. Model 74 allowed evaluating race as a predictor of trust in medical researchers, race as a predictor of information seeking, and the interaction between race and trust in medical researcher as a predictor of information seeking.

Race was identified as a significant predictor of trust in medical researchers, $F(1, 338) = 8.70, p < .01, R^2 = .03$. The evaluation of the beta coefficient, $b = -.31, t(338) = -2.95$, suggested that Caucasians are significantly more likely to trust medical researchers. For the evaluation of a complete model predicting information seeking, information-seeking self-efficacy and need for cognition were entered as covariates. Both information-seeking self-efficacy, $b = .35, t(334) = 4.24, p < .01$, and need for cognition, $b = .34, t(334) = 3.22, p < .01$, were significant covariates in the model. The model was significant, $F(5, 334) = 10.39, p < .01, R^2 = .15$, and showed that trust was a significant predictor of information seeking, $b = .23, t(334) = 2.51, p < .01$, while neither race, $b = -.23, t(334) = -1.41, p = .16$, nor the interaction between race and trust in medical researchers, $b = -.03, t(334) = -.16, p = .88$, were significant direct predictors of information seeking. This model suggests that trust in medical researchers is a mediator in the relationship between race and information behavior and supports H6.
Hypothesis 7

Hypothesis 7 predicted that African Americans are less likely than Caucasians to seek information. An analysis of variance was employed to test H7 and showed that there were significant differences between groups, \( F(1,338) = 4.83, p < .05, \eta = .01 \). Specifically, Caucasians were more likely to report information seeking (\( M = 5.38, SD = 1.44 \)) than African Americans (\( M = 5.00, SD = 1.71 \)). Significant relationships between information-seeking self-efficacy and need for cognition have been identified when assessing previous hypotheses. Therefore, an analysis of covariance with race as an independent variable, self-efficacy and need for cognition as covariates, and information seeking as a dependent variable was evaluated. The analysis resulted in a significant model, \( F(3,336) = 16.908, p < .01 \). Information-seeking self-efficacy, \( t(336) = 5.47, p < .01 \), and need for cognition, \( t(336) = 3.54, p < .01 \), had significant effects on information seeking, while the effect of race became insignificant, \( t(336) = -1.861, p = 0.06 \). Given the effect of covariates on information seeking, H7 was not supported.

Hypothesis 8

Hypothesis 8 predicted that race, trust in medical researchers, and information-seeking self-efficacy would predict information seeking (H8a) and behavioral intention to participate in clinical research (H8b). Serial mediation with PROCESS model 6 was used to test both hypotheses. To evaluate pathways predicting behavioral intention, race was entered as independent variable and trust in medical researchers, information-seeking self-efficacy, and information seeking as mediators. The model showed insignificant direct effect of race on behavioral intention, \( c` = - .19, t(335) = -1.22, p = .22 \), but a significant total effect, \( c = -.44, t(335) = -2.59, p < .01 \). The indirect effect of race on behavioral intention was also significant and showed a negative effect, effect = -
.25, 95% bias-corrected bootstrap CI (based on 5,000 samples) [-.434, -.100]. H8a was supported.

Subsequently, a model tested the relationship between race as the independent variable, trust in medical researchers, information-seeking self-efficacy, and information seeking as moderators, and behavioral intention as the dependent variable. The model showed four significant pathways that explain the relationship between race and behavioral intention to participate in clinical research. The pathways are summarized in Table 4-6 and graphically presented in Figure 4-2. Table 4-7 shows coefficients, standard error values, and p values for direct and indirect effects tested in the model.

Although all models show the overall negative relationship between participants who self-identified themselves as African Americans and their intention to participate in clinical research, trust in medical researchers, $t(335) = 4.51, b = .45, p < .01$, and information seeking behavior, $t(335) = 4.35, b = .26, p < .01$, minimize the negative effect and have direct positive effects on behavioral intention. Furthermore, information-seeking self-efficacy approached significance, $t(335) = 1.71, b = .14, p = .09$, suggesting its possible positive effect on behavioral intention. H8b was supported.

Table 4-6. Pathways to behavioral intention through information seeking

<table>
<thead>
<tr>
<th>Number</th>
<th>Pathway</th>
<th>Variables</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>$a_1b_1$</td>
<td>Race -&gt; Trust in Medical Researchers -&gt; Reduced Behavioral Intention</td>
</tr>
<tr>
<td>2</td>
<td>$a_1d_2b_2$</td>
<td>Race -&gt; Trust in Medical Researchers -&gt; Information-seeking Self-Efficacy -&gt; Reduced Behavioral Intention</td>
</tr>
<tr>
<td>3</td>
<td>$a_1d_3b_3$</td>
<td>Race -&gt; Trust in Medical Researchers -&gt; Information Seeking -&gt; Reduced Behavioral Intention</td>
</tr>
<tr>
<td>4</td>
<td>$a_1d_2d_3b_3$</td>
<td>Race -&gt; Trust in Medical Researchers -&gt; Information-seeking Self-Efficacy -&gt; Information Seeking -&gt; Reduced Behavioral Intention</td>
</tr>
</tbody>
</table>
Table 4-7. Path coefficients for a serial mediation model using race, trust in medical researchers, and information self-efficacy as predictors of behavioral intention

<table>
<thead>
<tr>
<th></th>
<th>b</th>
<th>Indirect Effect (95% CI)</th>
<th>SE</th>
</tr>
</thead>
<tbody>
<tr>
<td>a₁</td>
<td>-.308**</td>
<td></td>
<td>.105</td>
</tr>
<tr>
<td>a₂</td>
<td>-.037</td>
<td></td>
<td>.119</td>
</tr>
<tr>
<td>a₃</td>
<td>-.262</td>
<td></td>
<td>.170</td>
</tr>
<tr>
<td>b₁</td>
<td>.456***</td>
<td></td>
<td>.101</td>
</tr>
<tr>
<td>b₂</td>
<td>.140#</td>
<td></td>
<td>.082</td>
</tr>
<tr>
<td>b₃</td>
<td>.255***</td>
<td></td>
<td>.059</td>
</tr>
<tr>
<td>d₁₁</td>
<td>.246***</td>
<td></td>
<td>.073</td>
</tr>
<tr>
<td>d₃₁</td>
<td>.238**</td>
<td></td>
<td>.098</td>
</tr>
<tr>
<td>d₃₂</td>
<td>.369***</td>
<td></td>
<td>.083</td>
</tr>
<tr>
<td>c'</td>
<td>-.188</td>
<td></td>
<td>.151</td>
</tr>
<tr>
<td>c</td>
<td>-.440**</td>
<td></td>
<td>.170</td>
</tr>
<tr>
<td>a₁b₁</td>
<td></td>
<td>-.140 (-.263, -.045)</td>
<td>.085</td>
</tr>
<tr>
<td>a₁d₁₁b₂</td>
<td></td>
<td>-.011 (-.032, -.001)</td>
<td>.008</td>
</tr>
<tr>
<td>a₁d₃₁b₃</td>
<td></td>
<td>-.019 (-.053, -.004)</td>
<td>.011</td>
</tr>
<tr>
<td>a₂d₂₁b₂</td>
<td></td>
<td>-.007 (-.021, -.002)</td>
<td>.004</td>
</tr>
<tr>
<td>a₂d₂₁d₃₂b₃</td>
<td></td>
<td>-.005 (-.060, .027)</td>
<td>.020</td>
</tr>
<tr>
<td>a₃b₂</td>
<td></td>
<td>-.003 (-.027, .019)</td>
<td>.011</td>
</tr>
<tr>
<td>a₃b₃</td>
<td></td>
<td>-.067 (-.189, .009)</td>
<td>.048</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>-.252 (-.436, -.097)</td>
<td>.085</td>
</tr>
</tbody>
</table>

* p < .05; ** p < .01; *** p < .001, #p < .10, CI = bias-corrected bootstrap confidence interval, SE = Standard Error

Figure 4-10. Path coefficients for the serial mediation model of race and behavioral intention to participate in clinical research.
Hypothesis 9

Hypothesis 9 predicted that perceived uncertainty, uncertainty appraisal, information behavior, and information-seeking self-efficacy comprise an explanatory model of decision-making during recruitment for clinical research. PROCESS Model 6 was used to assess a serial mediation comprising of decisional conflict toward participation in a clinical study, threat and challenge uncertainty appraisal, behavioral intention to participate in a clinical study. Two models, with information seeking and information avoidance, were evaluated. Need for cognition, trust in medical researchers, and information-seeking self-efficacy were included as covariates in order to account for their influence on behavioral intention. The first model focused on the role of information seeking as a mediator of situational decision-making. The model showed an insignificant direct effect of uncertainty on behavioral intention, $c' = .12, t(335) = -1.32, p = .19$, but a significant total effect, $c = -.29, t(335) = -3.29, p < .01$. The indirect effect of uncertainty on behavioral intention was significant and negative, effect $= -.30, 95\%$ bias-corrected bootstrap CI (based on 5,000 samples) $[-.421, -.199]$.

Figure 4-11. A serial mediation model with uncertainty appraisal and information seeking as mediators of the effect of study-related uncertainty on behavioral intention to participate in a randomized clinical trial.
Table 4-8. Pathways to behavioral intention through information seeking

<table>
<thead>
<tr>
<th>Number</th>
<th>Pathway</th>
<th>Variables</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>$a_1d_2b_2$</td>
<td>Uncertainty -&gt; Threat -&gt; Challenge -&gt; Decreased Behavioral Intention</td>
</tr>
<tr>
<td>2</td>
<td>$a_1d_2d_3b_3$</td>
<td>Uncertainty -&gt; Threat -&gt; Challenge -&gt; Information Seeking -&gt; Decreased Behavioral Intention</td>
</tr>
<tr>
<td>3</td>
<td>$a_2b_2$</td>
<td>Uncertainty -&gt; Challenge -&gt; Decreased Behavioral Intention</td>
</tr>
<tr>
<td>4</td>
<td>$a_2d_3b_3$</td>
<td>Uncertainty -&gt; Challenge -&gt; Information Seeking -&gt; Decreased Behavioral Intention</td>
</tr>
<tr>
<td>5</td>
<td>$a_3b_3$</td>
<td>Uncertainty -&gt; Information Seeking -&gt; Decreased Behavioral Intention</td>
</tr>
</tbody>
</table>

Table 4-9. Path coefficients for a serial mediation model uncertainty, uncertainty appraisal, and information seeking as predictors of behavioral intention

<table>
<thead>
<tr>
<th></th>
<th>$b$</th>
<th>Indirect Effect (95% CI)</th>
<th>$SE$</th>
</tr>
</thead>
<tbody>
<tr>
<td>$a_1$</td>
<td>.192**</td>
<td></td>
<td>.073</td>
</tr>
<tr>
<td>$a_2$</td>
<td>-.316***</td>
<td></td>
<td>.051</td>
</tr>
<tr>
<td>$a_3$</td>
<td>-.151</td>
<td></td>
<td>.086</td>
</tr>
<tr>
<td>$b_1$</td>
<td>.009</td>
<td></td>
<td>.053</td>
</tr>
<tr>
<td>$b_2$</td>
<td>.760***</td>
<td></td>
<td>.096</td>
</tr>
<tr>
<td>$b_3$</td>
<td>.115*</td>
<td></td>
<td>.054</td>
</tr>
<tr>
<td>$d_{21}$</td>
<td>-.146***</td>
<td></td>
<td>.045</td>
</tr>
<tr>
<td>$d_{31}$</td>
<td>.046</td>
<td></td>
<td>.054</td>
</tr>
<tr>
<td>$d_{32}$</td>
<td>.617***</td>
<td></td>
<td>.092</td>
</tr>
<tr>
<td>$c'$</td>
<td>-.116</td>
<td></td>
<td>.088</td>
</tr>
<tr>
<td>$c$</td>
<td>-.285***</td>
<td></td>
<td>.087</td>
</tr>
<tr>
<td>$a_1b_1$</td>
<td>.002 (-.022, .022)</td>
<td></td>
<td>.011</td>
</tr>
<tr>
<td>$a_1d_2b_2$</td>
<td>-.021 (-.050, -.006,)</td>
<td></td>
<td>.011</td>
</tr>
<tr>
<td>$a_1d_3b_3$</td>
<td>.001 (-.001, .006)</td>
<td></td>
<td>.002</td>
</tr>
<tr>
<td>$a_1d_2d_3b_3$</td>
<td>-.002 (-.007, -.001)</td>
<td></td>
<td>.002</td>
</tr>
<tr>
<td>$a_2b_2$</td>
<td>-.240 (-.349, -.150)</td>
<td></td>
<td>.052</td>
</tr>
<tr>
<td>$a_2d_3b_3$</td>
<td>-.022 (-.052, -.004)</td>
<td></td>
<td>.012</td>
</tr>
<tr>
<td>$a_3b_3$</td>
<td>-.017 (-.058, -.003)</td>
<td></td>
<td>.014</td>
</tr>
<tr>
<td>Total</td>
<td>-.300 (-.421, -.196)</td>
<td></td>
<td>.058</td>
</tr>
</tbody>
</table>

* $p < .05; ** p < .01; *** p < .001, CI = bias-corrected bootstrap confidence interval, $SE = Standard Error$

The information-seeking model revealed five significant indirect pathways that predict behavioral intention as summarized in Table 4-8; path coefficients are presented in Table 4-9. Although the overall effect of uncertainty on behavioral intention is
negative, two of the mediators also have direct positive effects on behavioral intention. Challenge appraisal, \( t(332) = 7.88, b = .76, p < .01 \), and information seeking, \( t(332) = 2.11, b = .11, p < .05 \), demonstrated a positive relationship with behavioral intention to participate in clinical research.

**Table 4-10. Pathways to behavioral intention through information avoidance**

<table>
<thead>
<tr>
<th>Number</th>
<th>Pathway</th>
<th>Variables</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>a₁d₂₁b₂</td>
<td>Uncertainty -&gt; Threat -&gt; Challenge -&gt; Decreased Behavioral Intention</td>
</tr>
<tr>
<td>2</td>
<td>a₁d₃₁b₃</td>
<td>Uncertainty -&gt; Threat -&gt; Information Avoidance -&gt; Increased Behavioral Intention</td>
</tr>
<tr>
<td>3</td>
<td>a₂b₂</td>
<td>Uncertainty -&gt; Challenge -&gt; Decreased Behavioral Intention</td>
</tr>
</tbody>
</table>

**Table 4-11. Path coefficients for a serial mediation model uncertainty, uncertainty appraisal, and information avoidance as predictors of behavioral intention**

<table>
<thead>
<tr>
<th></th>
<th>( b )</th>
<th>Indirect Effect (95% CI)</th>
<th>( SE )</th>
</tr>
</thead>
<tbody>
<tr>
<td>a₁</td>
<td>.192**</td>
<td></td>
<td>.073</td>
</tr>
<tr>
<td>a₂</td>
<td>-.316***</td>
<td></td>
<td>.051</td>
</tr>
<tr>
<td>a₃</td>
<td>-.088</td>
<td></td>
<td>.100</td>
</tr>
<tr>
<td>b₁</td>
<td>-.009</td>
<td></td>
<td>.053</td>
</tr>
<tr>
<td>b₂</td>
<td>.820***</td>
<td></td>
<td>.096</td>
</tr>
<tr>
<td>b₃</td>
<td>.115*</td>
<td></td>
<td>.054</td>
</tr>
<tr>
<td>d₁₂</td>
<td>-.146***</td>
<td></td>
<td>.045</td>
</tr>
<tr>
<td>d₃₁</td>
<td>.610***</td>
<td></td>
<td>.071</td>
</tr>
<tr>
<td>d₃₂</td>
<td>.083</td>
<td></td>
<td>.122</td>
</tr>
<tr>
<td>c'</td>
<td>-.117</td>
<td></td>
<td>.088</td>
</tr>
<tr>
<td>c</td>
<td>-.285***</td>
<td></td>
<td>.087</td>
</tr>
<tr>
<td>a₁b₁</td>
<td>.008 (-.048, .010)</td>
<td></td>
<td>.013</td>
</tr>
<tr>
<td>a₁d₁₂b₂</td>
<td>-.023 (-.055, -.006)</td>
<td></td>
<td>.012</td>
</tr>
<tr>
<td>a₁d₁₃b₃</td>
<td>.012 (.002, .036)</td>
<td></td>
<td>.008</td>
</tr>
<tr>
<td>a₁d₁₂d₃₂b₃</td>
<td>-.001 (-.002, .001)</td>
<td></td>
<td>.001</td>
</tr>
<tr>
<td>a₂b₂</td>
<td>-.259 (-.375, -.167)</td>
<td></td>
<td>.053</td>
</tr>
<tr>
<td>a₂d₃₂b₃</td>
<td>-.003 (-.015, .004)</td>
<td></td>
<td>.004</td>
</tr>
<tr>
<td>a₂b₃</td>
<td>-.009 (-.043, .007)</td>
<td></td>
<td>.012</td>
</tr>
<tr>
<td>Total</td>
<td>-.289 (-.407, -.196)</td>
<td></td>
<td>.054</td>
</tr>
</tbody>
</table>

* \( p < .05 \); ** \( p < .01 \); *** \( p < .001 \), \( CI \) = bias-corrected bootstrap confidence interval, \( SE \) = Standard Error
Similarly, the model with information avoidance as a mediator revealed significant pathways explaining behavioral intention. Pathways are shown in Table 4-10; direct and indirect path coefficients are presented in Table 4-11 and graphically depicted in Figure 4-12. Here, one of the pathways, \( a_1d_3b_3 \), from uncertainty to threat and information avoidance showed that uncertainty management that follows this pathway could increase intentions to participate in clinical research. H9a was supported.

Figure 4-12. A serial mediation model with uncertainty appraisal and information avoidance as mediators of the effect of study-related uncertainty on behavioral intention to participate in a randomized clinical trial.

**Research Question Exploration**

**Research Question 1**

Research question 1 sought to explore the differences in the information behavior and content that attracts attention among health consumers who experience probabilistic uncertainty related to randomization or evaluative uncertainty related to cancer risk information. A Pearson’s correlation was used to determine the associations between probabilistic and evaluative uncertainty and information behavior. Probabilistic uncertainty was associated with information avoidance, \( r(340) = .21, p < .01 \), and
interest in information about aspirin as a cancer prevention drug, $r(340) = .15, p < .01$.

Evaluative uncertainty was associated with information seeking, $r(340) = .22, p < .01$,

interest in information about aspirin as a cancer prevention drug, $r(340) = .18, p < .01$,

and a fewer number of accessed questions about cancer, $r(340) = -.13, p < .01$. No other significant relationships were observed in the data.

**Research Question 2**

Research question 2 asked about the differences between males and females in uncertainty appraisal related to participation in a clinical research study. An analysis of variance was done to assess the differences in cognitive and affective appraisal of uncertainty. The difference in threat appraisal approached significance, $F(1,338) = 3.65, p = .57$ with males reporting stronger threat appraisal ($M = 3.09, SD = 1.64$) than females ($M = 2.76, SD = 1.51$). No differences were observed between males ($M = 5.65, SD = .92$) and females ($M = 5.70, SD = 1.05$) for cognitive challenge appraisal, $F(1,338) = .22, p = .63$. Similarly, no differences were observed between males ($M = 3.69, SD = 1.61$) and females ($M = 3.50, SD = 1.54$) for affective threat appraisal, $F(1,338) = 1.26, p = .26$. Finally, the differences between males ($M = 4.99, SD = 1.05$) and females ($M = 4.72, SD = 1.36$) were significant for affective challenge appraisal, $F(1,338) = 4.13, p < .05$.

**Research Question 3**

Research question 3 asked about the extent to which gender is a predictor of the appraisal-information seeking relationship. To answer RQ3 and evaluate the role of gender as a predictor in the relationship, two hierarchical regression models were assessed, one examining information seeking and another examining information avoidance as the dependent variables. Each model was entered in three steps. First,
information preference for decision-making autonomy, trust in medical researchers, 
need for cognition, information-seeking self-efficacy, and clinical trial knowledge were 
entered as covariates. Next, threat and opportunity appraisal were entered. Finally, 
gender was entered as the predictor controlled for other previously entered variables.

The first model was used for information seeking as the dependent variable. The 
first block of covariates was significant and accounted for 17% of the variance, \( F(5, 334) = 13.36, p < .01, R^2 = .15 \). In the second block, threat and opportunity appraisals were 
added. Together, they accounted for 23%, \( F(7, 332) = 13.81, p < .01, R^2 = .23 \). Finally, 
gender was added as the final predictor. The final model accounted for 24% and was 
significant, \( F(8, 331) = 12.85, p < .01, R^2 = .23 \). Standardized beta scores and standard 
errors for all three steps of the model are shown in Table 4-12.

Table 4-12. Beta scores and standard errors for the role of gender in predicting 
information seeking

<table>
<thead>
<tr>
<th>Predictor variable</th>
<th>( \beta ) (SE)</th>
<th>95% CI</th>
<th>( R^2 )</th>
<th>( \Delta R^2 )</th>
<th>( F )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information-seeking self-efficacy</td>
<td>.33 (.07)***</td>
<td>[.19, .48]</td>
<td>.167</td>
<td></td>
<td>13.36***</td>
</tr>
<tr>
<td>Clinical trial knowledge</td>
<td>-.31 (.10)**</td>
<td>[-.51, -.11]</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trust in medical researchers</td>
<td>.20 (.09)*</td>
<td>[.04, .37]</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Need for cognition</td>
<td>.42 (.10)***</td>
<td>[.22, .62]</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information seeking preference</td>
<td>.03 (.09)</td>
<td>[-.15, .21]</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Step 2</td>
<td></td>
<td></td>
<td></td>
<td>.226</td>
<td>.06</td>
</tr>
<tr>
<td>Threat appraisal</td>
<td>.04 (.06)</td>
<td>[-.08, .17]</td>
<td></td>
<td></td>
<td>13.81***</td>
</tr>
<tr>
<td>Challenge appraisal</td>
<td>.49 (.10)***</td>
<td>[.30, .68]</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Step 3</td>
<td></td>
<td></td>
<td></td>
<td>.237</td>
<td>.01</td>
</tr>
<tr>
<td>Gender</td>
<td>-.35 (.16)*</td>
<td>[-.65, -.04]</td>
<td></td>
<td></td>
<td>12.85***</td>
</tr>
</tbody>
</table>

* \( p < .05; ** p < .01; *** p < .001; # = .06 \)

The second model examined the role of gender in information avoidance. The 
first block of covariates was significant and accounted for 15% of variance, \( F(5, 334) = \)
11.86, \( p < .01 \), \( R^2 = .15 \). In the second block, threat and opportunity appraisals were added. Together, they accounted for 26\%, \( F(7, 332) = 17.00, p < .01, R^2 = .26 \). Finally, gender was added as the final predictor. The final model accounted for 27\% and was significant, \( F(8, 331) = 15.52, p < .01, R^2 = .27 \). Standardized beta scores and standard errors for all three steps of the model are shown in Table 4-12.

The results of the data analyses showed that gender is a significant predictor for both information seeking, \( \beta = .35, t(331) = -2.23, p < .05 \), and information avoidance, \( \beta = -.36, t(331) = -2.02, p < .05 \). Standardized beta scores suggest that male participants reported both greater information seeking and information avoidance.

Table 4-13. Beta scores and standard errors for the role of gender in predicting information avoidance

<table>
<thead>
<tr>
<th>Predictor variable</th>
<th>( \beta(SE) )</th>
<th>95% CI</th>
<th>( R^2 )</th>
<th>( \Delta R^2 )</th>
<th>( F )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information-seeking self-efficacy</td>
<td>( .24 (.09)** )</td>
<td>( [.07, .41] )</td>
<td>.151</td>
<td>.11</td>
<td>11.86***</td>
</tr>
<tr>
<td>Clinical trial knowledge</td>
<td>( -.32 (.12)** )</td>
<td>( [-.56, -.08] )</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trust in medical researchers</td>
<td>( -.09 (.10) )</td>
<td>( [-.29, .11] )</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Need for cognition</td>
<td>( -.29 (.12)^* )</td>
<td>( [-.53, -.05] )</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information seeking preference</td>
<td>( -.53 (.11)*** )</td>
<td>( [-.75, -.32] )</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Step 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Threat appraisal</td>
<td>( .52 (.07)*** )</td>
<td>( [.37, .66] )</td>
<td>.264</td>
<td>.11</td>
<td>17.00***</td>
</tr>
<tr>
<td>Challenge appraisal</td>
<td>( .05 (.11) )</td>
<td>( [-.17, .27] )</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Step 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>( -.36 (.18)^* )</td>
<td>( [-.71, -.01] )</td>
<td>.273</td>
<td>.01</td>
<td>15.52***</td>
</tr>
</tbody>
</table>

* \( p < .05 \); ** \( p < .01 \); *** \( p < .001 \)
CHAPTER 5
DISCUSSION

The goal of this study was to assess the role of uncertainty in decision making related to participation in clinical research. Health decisions for many health consumers are associated with uncertainty, and effective health communication and dissemination of health information can inform decision-making. Uncertainty is pervasive in health contexts; its role in informed decision-making and its possible effect on individuals’ well-being are challenging theoretical constructs that require comprehensive understanding to inform the practice of health delivery (Han, Klein, & Arora, 2011). Although not all situations involving uncertainty can be fully resolved through information provision, information avoidance can lead to uninformed decision-making. Thus, strategies of uncertainty management should be closely examined in various health contexts to identify when and how consumers can be provided with information to improve health outcomes and support decision-making. A decision to participate in clinical research, for example, is an example of a situation involving uncertainty that any health consumer could face. Information provision is the core characteristic of an ethical recruitment process, and it is, therefore, paramount to understand the pathways that lead to truly informed participation decisions.

Uncertainty is unavoidable in the context of clinical research, including initial recruitment, informed consent, retention, or subsequent result dissemination stages. The main finding of this study is that although uncertainty had an overall negative effect on participation in clinical research, the path from higher uncertainty to lower behavioral intention is not direct, and uncertainty itself was not found to be a direct predictor of participation or non-participation in clinical research. This finding allows concluding that
knowledge translation and dissemination efforts should account for the prospective participants’ uncertainty management needs rather than focusing primarily on minimizing uncertainty contained in study description and recruitment messages. The following sections discuss the results of the study, theoretical and practical implications of the findings, limitations identified, and directions for future research.

**Study Findings**

In evaluating the pathways to informed behavioral intention to participate in clinical research, this study looked at uncertainty appraisal and information behavior as the core aspects of uncertainty management. First, it explored uncertainty management from the perspective of knowledge translation. Specifically, it evaluated the differences in uncertainty appraisal and management in response to probabilistic and evaluative uncertainty to gain a better understanding of the nature of uncertainty related to participation in clinical research and its subsequent management. Second, it assessed the implications of uncertainty appraisal for information dissemination, focusing on the role of uncertainty appraisal in explaining information behaviors in response to uncertainty. Third, it expanded the application of uncertainty management theory as an explanatory model that links uncertainty, uncertainty appraisal, and information behavior to understand the pathways to decisions related to participation in clinical research. These three topical areas will be used to organize the discussion of the study findings presented next.

**An Uncertainty Management Perspective on Knowledge Translation**

The nature of uncertainty has been explicated to include probabilistic and evaluative orientations that can develop independently and affect one’s evaluation of a phenomenon (Babrow, 1992). Most current research identifies effective communication
about clinical study details, randomization, and prospective outcomes the key challenges of the recruitment process (Friedman et al., 2014; Krieger et al., 2015). Thus, the first goal of this study was to explore the sources of uncertainty associated with participation in a clinical study, including uncertainty about randomization into a particular study condition, or probabilistic uncertainty about what might happen should a volunteer decide to participate in the study, and uncertainty about benefits and risks of prospective participation in a study, or evaluative uncertainty about whether participation in a study is good or bad.

This dissertation constituted an initial effort in empirically assessing the role of probabilistic and evaluative uncertainty (H5a-c) in recruitment messages and identifying the differences in uncertainty management strategies in response to these sources of uncertainty. Most previous examinations of problematic integration focused on qualitative examination of probabilistic and evaluative uncertainty and provided a rich foundation for experimental research. Based on previous research, this study developed measurement scales to assess the degree to which participants perceive as uncertain the presence of randomization or possible exposure to cancer risk information. The scales have content validity because they contained items that correspond to the content domains (e.g., understanding of randomization and ambiguity) of other established scales (e.g., Knowledge about Clinical Trials Scale, Ellis et al., 2001, and Griffin Index of Ambivalence, Thompson et al., 1995). The measurement also has convergent validity. Previous work that examined the differences between probabilistic and evaluative uncertainty noted that these two forms of uncertainty can interact and affect one another (Ford et al., 1996). Finally, the developed scales showed face validity.
and successfully captured uncertainty experienced by experiment participants in response to message stimuli.

This study showed that uncertainty about the valence of the participation outcomes explain uncertainty toward participation (H5b), but randomization and possible factual outcomes of participation in clinical research do not (H5a). Next, this study showed that interaction between probabilistic and evaluative uncertainty is a significant predictor of uncertainty toward participation in clinical research (H5c). Introduction of probabilistic uncertainty, therefore, suggests that the prospects of possible gains and losses from participation in a clinical study are weighted relative to the probability of their occurrence.

Another interesting finding associated with probabilistic and evaluative uncertainty is their relation to information behavior (RQ1). This study showed that probabilistic uncertainty was positively correlated with information avoidance (but not information seeking) while evaluative uncertainty was positively correlated with information seeking (and not information avoidance). The positive bilateral correlations between those pairs of uncertainty and information behavior signal that the nature of uncertainty experienced by information consumers could play a role in explaining the different strategies for uncertainty management that could be employed by people in seemingly similar health situations, such as a decision to participate in a clinical study.

Implications of Uncertainty Appraisal for Information Dissemination

The second goal of this dissertation was to evaluate the role of uncertainty appraisal in explaining information seeking and avoidance behaviors. UMT, based on prior stress and uncertainty management work (Lazarus & Folkman, 1984), posits that response to uncertainty can manifest in either threat appraisal or challenge appraisal. It
also states that individuals can choose to actively seek or avoid information related to the uncertainty context. However, the underlying mechanisms of the relationship between appraisal and information behavior are unclear.

This study showed that differences in information behaviors can be explained by appraisal processes (H2a-c). Specifically, threat appraisal was found to be predictive of information avoidance while challenge appraisal predicted information seeking. Earlier research has shown that both negative and positive feelings toward information about clinical research can result in information seeking (Yang et al., 2010b; Yang & Kahlor, 2012). The explanatory model tested in this dissertation (H9) also showed that while these appraisals can act independently, as shown in Table 4-7 and 4-9, they also frequently act as serial mediators. This finding also supports the original framework conceptualized by Lazarus and Folkman (1984), who suggested that threat and challenge appraisals should be evaluated and studied for their concurrent effects. Theoretical implications of this finding are addressed later in this chapter.

The role of appraisal and self-efficacy were also evaluated as predictors of information behavior (H3a-c). First, self-efficacy was found to be a direct predictor of both information seeking and information avoidance. The theory of motivated information management (Afifi & Weiner, 2004) could provide a conceptual explanation for this empirical finding. The theory includes information self-efficacy as one of its key constructs and posits that individuals assess the outcomes and importance of an information behavior prior to engaging in it. Therefore, greater self-efficacy would mean that individuals are able to assess whether they want to look for information or avoid it. Yet, those with low self-efficacy would be more dependent on the information that is
provided and readily available to them. Furthermore, information skill trainings would be expected to result in greater confidence to look for information but not in a direct increase in information seeking behaviors. Applied to the context of recruitment for participation in clinical research, this finding indicates that information avoidance in the process of the provision of informed consent should be assessed in tandem with information-seeking self-efficacy. It could signal the inability to look for information to make an informed choice, or it could mean that prospective participants are accepting that more information is not always better and are making an informed choice to avoid some information.

Several other cognitive and sociodemographic factors were evaluated for their role in explaining the relationship between uncertainty appraisal and information behavior, namely need for cognition (H4), trust (H6), race (H7), and gender (RQ2 and 3). Need for cognition was found to be a significant predictor for information seeking but failed to reach significance as a predictor of information avoidance ($\beta = -0.22$, $t(335) = -1.90$, $p = .06$). Although this relationship was marginally significant, its direction in combination with threat appraisal as a significant predictor signals that information avoidance could be a protective mechanism against information overload (Misra & Stokols, 2012) or an indicator of a cognitive pathway in response to uncertainty (Petty et al., 1984). Additional investigation of the factors that explain and lead to information avoidance could assess the extent to which the need for cognition acts as a persistent cognitive indicator or has a more situational manifestation.

Next, the assessment of the role of trust showed its positive effect on information seeking, which, in line with previous research (Hesse et al., 2005), suggests that
information behavior, at least in part, is influenced and determined by social factors. Consequently, once trust was entered as a covariate for the examination of race and information seeking behavior, no differences were observed between Caucasian and African American participants. Furthermore, when behavioral intention was introduced as a dependent variable for a mediation model that included race, trust in medical researchers, information self-efficacy, and information seeking (H8), there was no direct effect of race on intention to join a clinical study, which is consistent with existing evidence (Fisher & Kalbaugh, 2011). However, the negative relationship between race and trust in medical researchers explained lower levels of information seeking and lower intentions to join a clinical study among African Americans compared to Caucasians, which is documented by a significant number of papers and systematic reviews (e.g., George et al., 2014; Moreno-John et al., 2004; Murthy et al., 2004). This finding allows the conclusion that race is not a direct predictor of participation in clinical research; it also shows that more efforts are necessary to increase trust in medical research among minority populations.

Finally, the assessment of the effect of gender in the process of uncertainty management showed that males were more likely to look for information about clinical research than females but were also more likely to avoid it actively. In other words, males reported more intentional behaviors related to information about clinical research. An earlier study that looked at the differences between communication behaviors of males and females in response to health-related information showed that although the number of males who reacted to health information was lower than females, those who actively reacted were more engaged with information by posting more comments and
sharing a larger number of posts (Strekalova, 2016). Similarly, it could be that males invited to participate in clinical research are intentional in their choice of information behavior related to clinical research.

**Pathways to Clinical Research Participation Decisions**

The third goal of this study was to examine whether uncertainty about participation in clinical research, uncertainty appraisal, and information behavior comprise a model explaining behavioral intention to participate in clinical research (H9a-b). Uncertainty management theory posits that uncertainty results in uncertainty appraisal, and this subsequently predicts information behavior. This study tested this model as a serial mediation and extended its application to predict intention to participate in a clinical research study. Acknowledging that information seeking and information avoidance are distinct behaviors, this study tested pathways for these behaviors separately.

Overall, the modeling of pathways for behavioral intention showed that uncertainty has a negative effect on behavioral intention. However, this effect is indirect and mediated through appraisal and/or information behavior. Applied to information seeking (H9a), several pathways to the decision to participate in clinical research have emerged. Some of the pathways, through threat and opportunity appraisal or just through opportunity appraisal, did not involve information seeking as a mediator. The pathways also showed that both threat and opportunity appraisal can be involved simultaneously in the management of uncertainty related to participation in clinical research. When information avoidance was entered as a mediator in the model (H9b), it showed a link from uncertainty to threat appraisal and information avoidance to behavioral intention. As discussed earlier, threat appraisal predicted the avoidance of
information about clinical research. However, information avoidance was shown to have a positive relation with behavioral intention. This finding has implications for the provision of informed consent as it indicates that prospective research participants could choose to be uninformed while still making a decision to join a research study. Although information avoidance would expected as an attempt to reduce behavioral obligation (Howell & Shepperd, 2012), prior research has shown that increased knowledge about a clinical study could have a negative effect on participation decisions (Ellis et al., 2001).

**Contributions to Communication Theory**

The major focus of the present study was to test the applicability of the uncertainty management theory in a context of recruitment for clinical research and extended the theory to explain behavioral intention for participation in clinical research. Strategic message design needs to account for an array of characteristics, including linguistic choices, affective communication outcomes, the role of messages as decision-making support tools, persuasive properties, and many more (Maibach & Parrott, 1995). However, looking at all—or a large number of these characteristics—at the same time is impossible. This study focused on the presentation of uncertainty in a research recruitment message and the understanding of the cognitive and behavioral outcomes associated with uncertainty.

Given the complexity of the tested relationships between the constructs of interest, this section will provide a discussion of the overall contributions of this study to the field of communication science. Specifically, the findings will be reviewed with a focus on how this research advanced knowledge with regard to communicating about information that is uncertain and supporting uncertainty management. The four main
areas to be discussed include the epistemology of uncertainty, processes associated with uncertainty appraisal, information behavior as uncertainty management strategy, and theoretical implications for uncertainty management as a precursor to behavioral intention.

**Epistemology of Uncertainty**

While it has been argued that the state of uncertainty is a subjective, cognitive experience and depends on the perceptions of individuals (Brashers, 2001), additional conceptualizations have focused on the properties of information (Babrow, 1992; Han, Klein, & Arora, 2011). Core challenges of supporting uncertainty management through strategic health communication efforts are defining uncertainty and identifying message properties that contribute to the heightening or reduction of the sense of uncertainty (Russell & Babrow, 2011). It has been almost 25 years since the explication of the nature of uncertainty that includes probabilistic and evaluative components was introduced (Babrow, 1992). Several qualitative research efforts have confirmed the applicability of these two constructs in explaining the nature of uncertainty related to health (e.g., E. L. Cohen, 2009; Magnuson, 2013). However, measurement and empirical examination of these constructs has lagged behind. The proposed measures (see Appendix D) afford the opportunity for future examination of different forms of uncertainty as explanatory factors in human behavior and health communication outcomes. This study provided evidence that probabilistic and evaluative uncertainty both play a role in the making of decisions related to participation in clinical research. It also challenges the existing taxonomy of health-related uncertainty as conceptualized by Han and colleagues (Han, Klein, & Arora, 2011) who focused on the manifestations of probabilistic uncertainty such as probability of risks (e.g., 20% chance of a positive
outcome), ambiguity of risks (e.g., 10-30% chance of a positive outcome), and complexity of risk estimation (e.g., 20% chance of positive long-term outcome that depends on short-term outcomes). Acknowledging the importance of probabilistic uncertainty, this study also shows that additional, evaluative forms and manifestations of uncertainty should be considered.

The finding that probabilistic and evaluative uncertainty interact in predicting uncertainty toward participation in clinical research provides opportunities for future research. It could be that probabilistic uncertainty, which correlates with information avoidance, could explain some of the dynamics in patient-provider interactions. For example, previous research has found that physicians provided more information and were more engaged with high-participation patients who asked more questions during medical office visits. Similarly, this perspective on health information provision can explain why prospective study participants, experiencing probabilistic uncertainty about randomization and study outcomes, are unsatisfied with the information about clinical research that is provided to them (Madsen, Holm, & Riis, 2007). At the same time, the evidence that evaluative uncertainty correlates with information seeking and positively oriented challenge appraisal can explain the confirmation bias frequently exhibited by online health information seekers (Keselman, Browne, & Kaufman, 2008). These interpretations can be extended into a theoretical proposition that information behavior is, in part, a function of the nature of uncertainty.

**Antecedents and Moderators of Uncertainty Appraisal**

To investigate the role of uncertainty appraisal and uncertainty management in decisions to participate in clinical research among healthy volunteers, the specific hypotheses and research questions were largely drawn from the uncertainty
management theory (UMT, Brashers, 2001). UMT conceptualizes threat and challenge appraisals as non-exclusive processes that can be activated for the management of an uncertainty situation. UMT also explicitly includes self-efficacy as a potential moderator that interacts with uncertainty appraisal. Although appraisal is the core process in the process of uncertainty management, the discussion of its antecedents and consequences by the UMT is limited.

Consistent with the original conceptualization, this study found that both threat and challenge appraisal were significant mediators in explaining behavioral intention. Threat appraisal predicted information avoidance, while challenge appraisal predicted information seeking. These findings help understand why in a similar uncertainty situation some people seek information while others choose to avoid it; it also provides explanation to previous research findings that reported the lack of statistically significant relationships between treat appraisal and information seeking (Rains & Tukachinsky, 2015). Although some of the previous uncertainty management research ascribed threat and challenge appraisal as opposite signs or hypothesized about opposite effects as a result of the activation of these appraisal processes (e.g., Rains & Tukachinsky, 2015), the findings reported in this study provide evidence that the two appraisal processes are separate. This finding also allows putting forth a proposition that appraisal processes in response to uncertainty act as serial mediators in predicting information behaviors.

The original examination of appraisal by Lazarus suggested that threat and challenge appraisal are separate processes that can be activated in response to the same situation (Lazarus & Folkman, 1984). However, other lines of research that investigated the role of appraisal in behavior suggested parallel routes (Rogers, 1975;
Witte, 1992). The protection motivation theory and, to some extent, the extended parallel processing model have looked at threat and coping appraisal as separate mechanisms that explain management of an uncertain situation. Applied to the explanation of information behavior, these propositions hold. Threat appraisal was found to be predictive of information avoidance, which could be viewed as the activation of maladaptive coping, and challenge appraisal appeared as a direct predictor of information seeking, which can be indicative of adaptive coping. However, the data presented in this study also showed that threat and challenge appraisal can be activated in a linear rather than parallel fashion. One explanation to this finding could stem from the role of self-efficacy that, in study, was found to be a direct predictor of with threat and challenge appraisals but was linked only to challenge appraisal in previous theorizing (Rogers, 1975). Future studies could take a closer look at self-efficacy and response efficacy to examine their role in activating and linking threat and challenge appraisals.

In addition, the findings on uncertainty appraisal reported in this study provided a link between the nature of uncertainty, i.e., probabilistic or evaluative, and uncertainty appraisal, i.e., threat and challenge. Neither probabilistic nor evaluative uncertainty were identified as predictors of challenge appraisal, but both had direct positive effect on threat appraisal. At the same time, information-seeking self-efficacy was shown to act as a direct predictor for challenge appraisal but not threat appraisal. This finding extends the application of problematic integration theory and allows putting forth a proposition that the recognition of probabilistic or evaluative uncertainty results in the recognition of a potential loss, i.e., threat. At the same time, an individual’s positive
assess the skill to manage this uncertain probabilistic and/or evaluative knowledge results in the recognition of a potential positive outcome, i.e., challenge. Applied as an extension to the classical prospect theory (Kahneman & Tversky, 1979), this finding also helps explaining why gains associated with the assessment of individuals’ personal abilities are assessed more moderately than losses that are judged based on the assessment of the external factors.

**Information Behavior as Uncertainty Management Strategy**

UMT is based on the proposition that information seeking and active information avoidance are separate behaviors (Brashers, 2001). This study showed that information seeking and information avoidance can both be the outcomes of uncertainty management but be predicted by different forms of uncertainty appraisal. The finding that threat and challenge appraisals can act independently and simultaneously to explain behavioral intentions extends previous research and suggests the need to examine health communication efforts that could support challenge appraisal and facilitate uncertainty management for patients and information consumers who experience uncertainty. Some earlier research suggested that information seeking is more heavily influenced by negative affect while information avoidance is influenced by positive affect (Yang & Kahlor, 2012) as applied to climate change risks, but, applied to clinical research information, optimistic feelings (or challenge appraisal) have a positive effect on information seeking (Yang et al., 2010b).

This study also provided some explanation for the activation of different types of information behavior. Conceptually, self-efficacy to manage stressful or uncertain information is a predictor of uncertainty management (Brashers, 2001; Lazarus & Folkman, 1984). However, it has been both found to be a complete mediator (Rains,
2008) and a moderator (Mayer et al., 2007; Namkoong et al., 2010) explaining information seeking. In this study, information-seeking self-efficacy was evaluated as a predictor of information behavior in tandem with uncertainty appraisal; the results showed that information-seeking self-efficacy has a direct effect on information behavior. Furthermore, information behavior in response to threatening uncertain information resulted in information seeking only for those participants whose information-seeking self-efficacy was high. Both uncertainty appraisal and self-efficacy to respond to uncertainty have been previously identified as the key factors that contribute and explain uncertainty management. Applied to information-seeking self-efficacy, this study showed that these two constructs, appraisal and self-efficacy, have effects on uncertainty management but act independently. This finding seems to indicate that information consumers whose information-seeking self-efficacy is low are using alternative strategies to manage uncertainty, which could include the reliance on the strength of threat or challenge appraisal as a heuristic for decision-making.

Uncertainty Management and Behavioral Intention

A number of studies have looked at the role of information seeking in clinical trial recruitment and behavioral intention to participate but did not account for the effects of uncertainty (Yang et al., 2010a, 2010b). Some other studies have investigated pathways to information seeking and avoidance guided by the UMT but stopped short of theorizing or explaining the link from information consumption to health-related behaviors (Rains, 2008, 2014; Rains & Tukachinsky, 2015). This study addressed these gaps and showed that uncertainty has an effect on behavioral intention, but this effect is mediated by appraisal and information behavior. Specifically, extending the theory of uncertainty management (Brashers, 2001), uncertainty, uncertainty management, and
behavioral intention were shown to form a mediating relationship that provides a general framework linking uncertainty and behavior. Figure 5-1 provides a graphic depiction of this relationship.

Figure 5-1. Theoretical relationships among uncertainty, uncertainty management, and behavioral intention

All indirect pathways but one showed an inverse relationship between uncertainty and intention to participate, which means that a higher level of uncertainty is likely to result in a lower intention to participate in a clinical study. At the same time, both information seeking and information avoidance were found to be direct positive predictors of behavioral intention to participate in clinical research. Furthermore, one pathway showed that higher uncertainty can result in higher intention to participate; this pathway involved threat appraisal and information avoidance as mediators. This finding is consistent with UMT propositions that uncertainty management can manifest in uncertainty maintenance (Brashers, 2001). The extended application of UMT signals the need for new lines of research to provide better understanding of the information (e.g., volume, complexity, and mode of presentation) and information behavior (e.g., avoidance due to prior knowledge or experience and level of salience) factors. Also, additional studies are necessary to assess the extent to which behavioral intention to participate in clinical research manifest in actual behavior (e.g., agreement to join an actual study). Although initial controlled experimental studies should take place first to assess theoretical relationships among the constructs named above, research should
eventually be incorporated as part of recruitment and informed consent activities for open clinical studies as part of implementation research efforts that can provide evidence essential for practice of health communication and recruitment.

**Implications for Practice**

Results presented in this research provide actionable evidence for the practice of clinical trial recruitment, provision of informed consent for participation in clinical studies, and dissemination of information about clinical research. First, this study provides empirical evidence for the theoretical distinction between probabilistic and evaluative uncertainty that could be created by exposure to a clinical study recruitment message. In the context of clinical research, the inability to recognize the source of uncertainty has been challenging recruitment efforts and provision of informed consent. Surprisingly, objectively present uncertainty about study randomization explained decisional conflict in interaction with evaluative uncertainty but not independently. While study participants were uncertain about the study condition that could be assigned to them, they did not perceive that as a barrier for decision-making. Also, the data showed that the interaction between probabilistic and evaluative uncertainty leads to the reduction of uncertainty toward participation in clinical research.

Applied to the practice of clinical research recruitment, this finding suggests that evaluative information about possible risks and benefits of prospective research should be presented together with the probability of these risks and benefits. This also means that to reduce the uncertainty that is likely to be experienced by prospective study participants and, subsequently, to support their informed decision to participate (or not participate) in a clinical research study, evaluative information about participation should be shared with prospective study participants during recruitment and informed consent
efforts. For example, the information about randomization could be presented together with an explanation of the value of research for the progress of medical knowledge. Alternatively, information about possible side effects could be presented along the information that early identification of side-effects will contribute to the improvement of treatments. However, the presentation of evaluative information should be not be used as a persuasive tool to raise expectations of positive outcomes among prospective participants and, ideally, should undergo assessment prior to its inclusion in recruitment and consent materials.

In line with previous research, this study also showed that trust in medical researchers is an important factor explaining intentions to enroll in clinical research. Most recruitment activities for clinical research are initiated from medical offices, and a substantial amount of research has shown that interpersonal communication plays a role in explaining health care outcomes (Street, Makoul, Arora, & Epstein, 2009). Similarly, interpersonal communication related to clinical trial recruitment should be considered for its effects on participation decisions and study retention. For example, prospective participants should be encouraged to ask questions about clinical research in general and the study into which they are being recruited. Also, similar to preparing questions for health care providers before a clinical appointment (Cegala, 2003), prospective study participants could be given decision and communication aids to help them formulate questions before meeting with a research team for discussion about participation in a clinical study.

Next, this study has implications for the provision of informed consent. Previous research on the process of information provision related to participation in clinical
research noted that prospective participants might not be acquiring the information necessary for an informed decision about clinical research. This study showed that uncertainty appraisal and management are contributing factors as well. Although the overall effect of uncertainty on intention to participate was negative, challenge appraisal and information seeking were shown to be positive direct predictors of participation in a clinical research study. For the practice of recruitment in clinical research, this finding implies that prospective participants should be presented with information that allows them to evaluate the contributions that their research participation could make. They also should be supported in their information seeking as their decisions to participate in research studies maybe uninformed. For the logistics of clinical research recruitment, this could mean allocating time that would allow prospective participants to consult with their families, seek information from trusted sources, or learn about the questions that should be asked before making a decision about participation. Alternatively, health information skill training could be a part of quality improvement efforts across a wider range of situations when information seeking is essential for positive health outcomes or informed decision-making.

Finally, this study has implications for the strategic planning of efforts to disseminate information about clinical research that would support uncertainty management among prospective participants. The fact that challenge appraisal is a positive direct predictor of participation intentions suggests that helping prospective study participants recognize volunteering in clinical research as an opportunity for personal growth and contribution to the society could lead to positive recruitment outcomes. However, this study showed that challenge appraisal can be a direct
predictor of behavioral intention without the inclusion of information seeking behavior. Therefore, strategic communication and information dissemination efforts should be essential to ensure that decisions to participate in clinical research are informed beyond the appraisal of initial information. One frequently used health communication strategy is the use of narratives from patients or previous research participants (Hinyard & Kreuter, 2007). Building on the evidence of the positive role of challenge appraisal, a research participant who describe their research experience could be asked to share what participation in research meant to them beyond an opportunity to improve their own health.

Information consumers frequently use heuristics and shortcuts in evaluating information (Fiske & Taylor, 2013). Therefore, their information seeking in response to evaluative uncertainty could be used as an indicator that their opinions, which can be subsequently used as decision-making heuristics, have not been fully formed. These findings could inform the development of informational sites for the promotion of clinical research, which should include sufficient presentation and discussion of information that increases the public’s ability to form opinions (e.g., through the use of narratives) rather than only increasing literacy and knowledge about clinical research through factual information.

**Strengths and Limitations**

One of the key variables evaluated in the study was information seeking. Participants were limited to the pre-defined topics from which they could choose information and did not seek for information through freely available online sources. Therefore, this study provided a controlled assessment of information behavior that could be expected from visitors to a clinical recruitment site. Although participants self-
reported information-seeking intentions, observational measures were highly skewed and showed that the majority of survey participants read few information topics and spent little time doing so. By recoding information consumer activity associated with a controlled amount of information, this study provided a systematically measured record of information behaviors that would be observed by managers of any one online site providing similar information.

There are two key limitations of this study that warrant consideration. First, specifics of the experimental method may have limited some of the study’s external validity. While the unavailability to search freely may limit the external validity of this study, it was a necessary artifact of the experimental method used to test the hypotheses. In order to assess the effect of information behavior on behavioral intention to participate in clinical research, it was necessary to expose all participants to the same information. This design ensured that participants were not affected by additional, varying levels of uncertainty associated with prospective participation in clinical research. Furthermore, steps were taken to make information to which participants were exposed as realistic and relevant as possible. In addition, beyond examining whether or not participants selected a particular information topic to explore, and how much time was spent on each topic, the study did not examine the extent to which participants’ information needs were met or remained unsatisfied. Although information topics and content were adapted with minimal changes from active online sites that promote participation in clinical research, the level to which such content could and should be tailored to support health information seekers in their decision making and knowledge management should undergo further exploration.
A second limitation of this study is the use of an equal-size stratified sample. The exploration of hypotheses and research questions for this study allowed assessing the differences between two gender groups and two race groups, thus providing important evidence and contributing to further theoretical understanding of the processes associated with decisions in the context of clinical research. However, these results should be carefully considered before any generalizations about the characteristics of these demographic groups are made. Additional studies would be necessary to examine the interaction of race or gender with factors that contribute to lower levels of participation in clinical research.

**Future Research**

Investigation of the role of uncertainty management has implications for theory and practice related to health communication and dissemination of health-related information. Throughout the discussion of this study, suggestions have been made concerning potential scholarship. Opportunities for future research discussed thus far fall into two complimentary areas of research, strategic communication and information behavior.

As an umbrella term, strategic communication is concerned with purposeful communication and argues for a holistic understanding of communication that is concerned with both what messages are formulated and how they affect behavior (Hallahan, Holtzhausen, Ruler, Verčič, & Sriramesh, 2007). Accordingly, this study looked at both the content of recruitment messages and people’s information and decision-making behaviors in response to information that contains uncertainty. As the results showed, uncertainty about randomization outcomes is closely tied with uncertainty about the value of participating in clinical research. Furthermore, challenge
appraisal was identified as having a positive effect on intentions to participate in a clinical study. This highlights the need for message design studies that could provide additional evidence on the inclusion of factual and evaluative information in recruitment materials and assess the factors that promote hope and a sense of communal contribution through participation in a research study. This research did not evaluate how recruitment messages could be delivered. Future studies could look at the differences among available dissemination channels, including online forums, electronic medical records, and clinic check-in desks. Stepping outside of the laboratory experimentation environment, dissemination channels could be evaluated for their comparative cost efficiency and recruitment yield.

Information behavior was one of the main constructs of interest for this dissertation. A large body of research has been amassed that focuses on the different aspects of information behavior, including information seeking, passive reception, and active participation in the information exchange process (for a comprehensive review, see Case, 2012). The connection between active engagement with health information and positive health outcomes has been documented as well. Yet, less amount of evidence is available to explain the interrelations among situational information behavior, people’s health-related decisions, and their behavior related to health self-management. The results of this dissertation show that uncertainty management theory can be effectively applied to the context of dissemination of information about clinical research and extended to explain behavioral intentions. The model and identified pathways should undergo further development and testing to determine their viability in explaining and predicting participation decisions in different situations. In addition, this
dissertation looked at one source of information, an online recruitment message.

Accepting the ecological view of communication surrounding participation in clinical research (Street, Thompson, Dorsey, Miller, & Parrott, 2003), future studies using longitudinal designs could evaluate the nature and role of other sources of information about clinical research (e.g., mass media, physicians and other healthcare providers, other patients, and family members) and the role of interpersonal and mediated communication in the process of uncertainty management. Furthermore, as both information seeking and information avoidance were identified as having positive effects on behavioral intention to participate in a clinical study, additional research is needed to provide better understanding of the factors that interact with information behavior (e.g., the role of family communication, access to tailored and personalized information, complexity and salience of available information, and existing experiential knowledge related to clinical research).

Additional directions for future research could be informed by the national priorities. A recent funding announcement from the NIH (National Institutes of Health, 2016) identified the need for the research in the area of infodemiology, the science of information dissemination and its affordances in technology-mediated environments (Eysenbach, 2009). Health and health research topics are among the most popular on social media and online forums, and the data collected through these sources could provide both cross-sectional and longitudinal evidence of uncertainty, its management, and decisions related to participation in clinical research. Communities of patients, caregivers, researchers, and general audience supporters have been forming organically on social media platforms like Facebook (Facebook, 2015) and forums like
those supported by Inspire technology (Inspire, n.d.). Analysis of conversations and knowledge sharing that happens through these communities can provide insights related to conditions as rare as Pompe disease (Facebook, n.d.) and as broad as cardiovascular health for women (The National Coalition for Women with Heart Disease, n.d.). In addition, these communities could serve as partners in strategic communication efforts when members of the communities are approached to participate in the development and implementation of clinical research studies.

While experimental methods provide an opportunity for controlled examination of variables and relationships, observations of naturally occurring conversations can provide additional understanding of the information needs and behaviors of clinical research volunteers. In addition, electronic patient charts become new platforms that allow information seeking and exchange, and that call for research intersection of interpersonal and mass communication. For example, patients who have previously agreed to participate in clinical research could receive invitations to participate in clinical studies for which they qualify based on inclusion and exclusion criteria. Guided by the perspective on information processing (McGuire, 1968) that was discussed for its application to clinical research in the Introduction, the data about patient logins into the patient chart system and their click activity related to recruitment materials should be collected to assess the effectiveness of this communication strategy as a tool to increase general awareness about clinical research and attention to recruitment messages. Through their electronic medical charts, prospective participants also could receive an invitation to visit a micro-site with focused information about the background of the study and invited to submit any questions or comments about the study specifics.
Shared comments could be analyzed quantitatively across studies; they also can be analyzed qualitatively to identify any uncertainties and decisional conflicts that prospective study participants experience in relation to a particular clinical study. This information and communication behaviors could also be used as partial indicators of comprehension and antecedents of informed consent. As can be seen from this example of a possible series of interconnected studies, the areas of future research are relevant to the field of communication but also touch on the subjects of information technology, health informatics, health services research, and decision science. Therefore, successful knowledge translation and dissemination efforts call for interdisciplinary collaboration, thus establishing communication as a translational science discipline.

**Conclusion**

Understanding how uncertainty is managed is essential because important health-related decisions, such as participation in a clinical study, are frequently informed by limited, introductory knowledge. Uncertainty does not automatically result in information seeking, yet additional information seeking, which could be necessary for decision-making, is a behavior that is frequently encouraged and expected of health consumers. Simply providing prospective participants with additional information through web-sites and brochures is not enough because factors like information-seeking self-efficacy and trust in medical researchers could affect the uptake of readily available information. Instead, future studies should continue to investigate the ways in which strategic communication could be used to support health-related uncertainty management.
APPENDIX A
STIMULI

Research Study for Health Volunteers: Health Information on the Internet (No Probabilistic Uncertainty / No Evaluative Uncertainty)
Research Study for Health Volunteers: Disease Prevention and Aspirin (Probabilistic Uncertainty / No Evaluative Uncertainty)
Research Study for Health Volunteers: Cancer Prevention and Aspirin (No Probabilistic Uncertainty / Evaluative Uncertainty)
Research Study for Health Volunteers: Cancer Prevention and Aspirin (Probabilistic Uncertainty / Evaluative Uncertainty)
Health Information on the Internet

Health information on the Internet can have positive effect on people’s health, but looking for information can be a challenge.

**STUDY PROCEDURES**

All participants will be assigned to the same group and see the same information about a few general health topics.

We are looking for your comments about the information and what you find most interesting and useful.

This is a quality improvement project.

Your participation is completely voluntary and will contribute to health communication research.

Become a research volunteer. You can help improve the lives of people like you!
Disease Prevention and Aspirin

Daily use of aspirin can prevent many diseases, including heart disease, cancer, and rheumatoid arthritis.

**STUDY PROCEDURES**

The exact prevention dose for aspirin is **uncertain**. If you agree to participate, you will be **randomly assigned** to **one of the two groups**: to receive the dose of aspirin specifically calculated for you **OR a placebo**, a pill that will not have any effect on your health.

Millions of people are taking aspirin. Aspirin can reduce fever and relieve the pain from muscle aches, toothaches, common cold, and headaches.

This study will help learn how to best prevent pain.
Cancer Prevention and Aspirin

Earlier studies have shown that aspirin can reduce cancer risks and prevent many types of cancer.

**Study Procedures**

The best prevention dose of aspirin is the same amount that is currently prescribed for heart disease prevention. All participants in this study will be assigned to the same study group. Everyone who agrees to participate will receive the same dose of aspirin.

If you agree to participate in this study, you will also learn about your risks of developing cancer.

Before you participate in this study, you should decide if knowing your cancer risks is good or bad for you.

Become a research volunteer. You can help improve the lives of people like you!
Cancer Prevention and Aspirin

Earlier studies have shown that aspirin can reduce cancer risks and prevent many types of cancer.

**STUDY PROCEDURES**

The right prevention dose of aspirin is uncertain. If you agree to participate, you will be randomly assigned to one of the two groups: to receive the dose of aspirin specifically calculated for you OR a placebo, a pill that will not have any effect on your health.

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Become a research volunteer. You can help improve the lives of people like you!
**APPENDIX B**

**SELF-EFFICACY MANIPULATION**

<table>
<thead>
<tr>
<th>Condition</th>
<th>Message</th>
</tr>
</thead>
</table>
| High self-efficacy condition | **Persuasive message**  
Health information is essential and helpful. There is a lot of reliable and useful information available online about health and clinical research, and reading it helps making well-informed health decisions. In fact, many people feel secure that they can find relevant information about health and clinical research when they want and need it.  
**Free-text entry prompt**  
Please think about topics or questions related to clinical research that would be interesting to you personally. Please write a 2-3 of these topics or questions below. |

| Low self-efficacy condition | **Persuasive message**  
Health information is complex, ambiguous, and confusing. A lot of online information about health and clinical research is inconsistent, and reading this information makes it hard to make decisions. In fact, many people feel insecure about what they know about health and clinical research, and if they are able to find relevant information online.  
**Free-text entry prompt**  
Please think about the last time you’ve tried to find health information online. What were the *challenges* you experienced?  
Think about clinical research and information available about it online? In your opinion, why is this information complex and hard to understand? |
Cancer Basics

What is cancer?
Word count: 109

Cancer is a group of more than 100 different diseases characterized by the uncontrolled, abnormal growth of cells. These cells form a lump or mass called a tumor.

Doctors divide cancer into types based on where it began. The most common type is carcinoma. A carcinoma begins in the skin or the tissue that covers the surface of internal organs and glands. Carcinomas usually form solid tumors. Examples of carcinomas include prostate cancer, breast cancer, lung cancer, and colorectal cancer.

There are many other types of cancer. Some types of cancer do not form a tumor. These include leukemias, most types of lymphoma, and myeloma.

How does cancer begin?
Word count: 99

Cells are the basic units that make up the human body. Cells grow and divide to make new cells as the body needs them. Usually, when cells get too old or damaged, they die. Then new cells take their place.

Cancer begins when genetic changes impair this orderly process. Cells start to grow uncontrollably. These cells may form a mass called a tumor. A tumor can be cancerous or benign. A cancerous tumor is malignant, meaning it can grow and spread to other parts of the body. A benign tumor means the tumor can grow but will not spread.

How does cancer spread?
Word count: 114

As a cancerous tumor grows, the bloodstream or lymphatic system may carry cancer cells to other parts of the body. During this process, known as metastasis, the cancer cells grow and may develop into new tumors. One of the first places a cancer often spreads is to the lymph nodes. Lymph nodes are tiny, bean-shaped organs that help fight infection. They are located in clusters in different parts of the body, such as the neck, groin area, and under the arms.

Even if the cancer spreads, it is still named for the area where it began. For example, if breast cancer spreads to the lungs, it is called metastatic breast cancer, not lung cancer.
What do cancer risk estimates mean?
Word count: 112

Statistics are used to help doctors understand who is at risk for cancer. Several types of statistics are used to determine cancer risk for large groups of people: incidence, prevalence, and mortality. Understanding your risk of cancer can help you receive appropriate screening tests and make lifestyle choices to lower your cancer risk.

Many people may want to know their individual risk of being diagnosed with cancer. Statistics are used to determine the risk of cancer for groups of people and are often helpful to estimate your risk of cancer based on individual aspects that are similar to the groups at risk. However, statistics cannot tell you if you will develop cancer.

What are cancer risks?
Word count: 104

A risk factor is anything that increases a person's likelihood of developing cancer. Although risk factors, such as smoking or a family history of cancer, often influence the development of cancer, most do not directly cause cancer.

General risk factors for cancer include older age, a personal and/or family history of cancer, using tobacco, some types of viral infections (such as human papillomavirus or HPV), specific chemicals (such as benzene), and exposure to radiation (including ultraviolet radiation from sunlight). Although risk factors like using tobacco, being overweight, and getting multiple sunburns can be avoided, other risk factors cannot be controlled, such as getting older.

What is cancer screening?
Word count: 100

Scientists continue to develop tests that help find specific types of cancer before signs or symptoms appear. This is called screening. Screening tests can help doctors find a cancer at an earlier, more treatable stage. This may help improve survival. However, cancer screening also has a number of risks.

Screening tests may find slow-growing cancers that would not have caused any harm during a person's lifetime. As a result, some people may receive potentially harmful, painful, stressful, and/or expensive treatments that they did not need. Sometimes a screening test will suggest that a person has cancer when they do not.

What questions could I ask the doctor about cancer risks?
Word count: 110

It can be helpful to ask a member of your health care team to explain what cancer risk information means in the context of your everyday life. You may want to know how
losing weight, starting a new exercise plan, or being screened for early diabetes might benefit you.

Consider asking your doctor the following questions:
- What risk factors do I have, and how do they affect my risk of cancer?
- What is my chance of developing cancer in the next five years? In my lifetime?
- What can I do to lower my risk of cancer?
- What cancer screening tests do you recommend, and how often should I have them?
Clinical Research

What are clinical studies?
*Word count: 100*

Clinical studies are research studies that involve people. They are the final step in a long process that begins with research in a lab. Most treatments we use today are the results of past clinical studies. They take place in doctors’ offices, medical centers, community hospitals and clinics, and veterans’ and military hospitals.

Some patients may fear that enrolling in a study means they chance receiving no treatment at all for their disease, but the reality is that patients in clinical studies receive either the best treatment currently known for their disease, or a new, and possibly more effective, therapy.

What are prevention studies?
*Word count: 109*

Prevention trials are studies involving healthy people. For example, in cancer prevention trials, the participants either do not have a cancer but are at high risk for developing the disease or have had cancer and are at high risk for developing a new cancer. These studies look at cancer risk and ways to reduce that risk.

Prevention studies focus on finding out whether actions people take—such as exercising more or eating more fruits and vegetables—can prevent diseases. Other studies focus on finding out whether taking certain medicines, vitamins, minerals, or dietary supplements (or a combination of them) may lower the risk of a certain type of disease.

What are screening studies?
*Word count: 87*

The goal of screening trials is to test new ways to find disease early, when it may be more easily treated. Cancer screening studies are the most common. An effective screening test will reduce the number of deaths from the cancer being screened.

Researchers who conduct cancer screening studies want to know:
- Does finding disease earlier, before people have any symptoms, save lives?
- Is one screening test better than another?
- Do a large number of people who receive the screening test undergo unnecessary follow-up tests and procedures?

What is tissue research?
*Word count: 104*
Many medical tests involve human tissue, skin, hair, nails, blood, and urine. Doctor only takes the amount of tissue he or she needs for the medical test, and there may be some leftover tissue. Doctors usually destroy this unneeded tissue, but patients may choose to allow this leftover tissue to be stored and used for future research. People do not get to decide what kind of research your tissue is used in, just as people do not get to decide who gets the blood donated at a blood drive.

Research with tissue can help prevent and treat diseases such as cancer, diabetes, and Alzheimer’s.

Who participates in prevention studies?

Many people take part in prevention studies.

Men and women of all ages and backgrounds take part in these studies. Usually:
• They are healthy people.
• They are people who want to lower their chances for getting a certain disease.

Each study has different rules about who can join. For example: One study may have people of a certain age or sex. One study may have people with a certain family history.

There are prevention studies for men and women of all ages and backgrounds. You may know someone—a friend, relative, neighbor, or co-worker—in a study now.

What is random assignment to groups?

Frequently, people who join a study are placed in different groups. Each group takes a different medicine or vitamin. People are assigned to groups by chance, and each person has the same chance of being placed in any of the groups. No one can pick the group he or she is in. Neither the researchers nor the participants choose which group is assigned for the participant. This keeps the study fair, honest, and accurate.

Along the way, researchers will compare the groups to find out if there were any differences. Then they will be able to tell us which medicine or vitamin works the best.

What questions about clinical research should I ask?

Before participating in a clinical study, consider asking some of the questions below:
• What is the purpose of the study?
• Why do the researchers believe that the treatment being studied may be better than the one being used now? Why may it not be better?
• How long will I be in the study?
• What kinds of tests and treatments are involved?
• How will I be told about the study’s results?
• Who can I speak with about questions I have during and after the study?
• Who will be in charge of my care?
• Is there someone I can talk to who has been in the same or similar study?
APPENDIX D
MEASUREMENT OF PROBABILISTIC AND EVALUATIVE UNCERTAINTY

Probabilistic uncertainty

If I participate, my study group assignment will be determined by chance
If I participate, my study group assignment is uncertain
If I participate, my study group assignment will be randomly selected
If I participate, my study group assignment won’t be known in advance

Evaluative uncertainty

Information that I will learn in this study can be either good or bad for me
Information that I will learn in this study can be either pleasant or unpleasant for me
Information that I will learn in this study can be either favorable or unfavorable for me
Information that I will learn in this study can be either beneficial or harmful for me
Daily use of aspirin

What are the risks and benefits of aspirin use?
Word count: 98

There are risks and benefits to regular aspirin use, and the USPSTF weighed both in order to come up with their recommendation. The draft guidelines are recommending that certain adults in their 50s, who are at higher risk of a heart attack or stroke, and do not have risk factors for stomach bleeding, start taking low-dose aspirin daily to help prevent cardiovascular disease and colorectal cancer. Regular aspirin use can cause serious health problems such as stomach bleeding, which is why no public health organization, including the American Cancer Society, recommends taking aspirin solely to reduce cancer risk.

Can aspirin prevent heart attacks?
Word count: 115

Nonprescription aspirin is used to prevent heart attacks in people who have had a heart attack in the past or who have angina (chest pain that occurs when the heart does not get enough oxygen). Aspirin is also used to reduce the risk of death in people who are experiencing or who have recently experienced a heart attack. Nonprescription aspirin is also used to prevent ischemic strokes (strokes that occur when a blood clot blocks the flow of blood to the brain) or mini-strokes (strokes that occur when the flow of blood to the brain is blocked for a short time) in people who have had this type of stroke or mini-stroke in the past.

Can the daily use of aspirin play a role in preventing cancer?
Word count: 114

A recent study found that after 5 years of follow-up, trial participants who took aspirin daily—regardless of dose—had a 44 percent reduced risk of dying from cancer compared with participants who took a placebo. At a minimum, in combination with the appropriate screening, the data indicate that aspirin would be effective in preventing colon and breast cancer. The largest decrease in risk was for gastrointestinal cancers. However, doctors warn that it would be premature to recommend that people start taking aspirin specifically to prevent cancer. Potential side effects have to be taken into consideration, he continued, noting that even low dosages of aspirin “can substantially increase the risk of serious stomach bleeding.

What other studies need to be done to clarify whether aspirin can play a role in preventing cancer?
Word count: 108

The best study would be a randomized trial where tens of thousands of people would be randomly assigned to take aspirin or a placebo pill daily for at least 10 years.
Two types of ongoing studies will help clarify how long aspirin needs to be taken before any effects on cancer become apparent. First, there are randomized studies designed to study the effects of aspirin on heart disease – information from these same studies could be analyzed to study its effects on cancer as well. Second, there are high-quality “observational” studies that track large numbers of people for decades, asking for detailed information on aspirin use every few years.

Is the daily use of aspirin everyone?

Every prescription and over-the-counter medicine has benefits and risks—even such a common and familiar medicine as aspirin.

Daily use of aspirin can lower the risk of heart attack. Many medical professionals prescribe aspirin to patients who have heart disease or who have already had a heart attack or stroke. There may be a benefit to daily aspirin use for people who have some kind of heart or blood disease, or if there is evidence of poor blood flow to the brain.

However, the risks of long-term aspirin use may be greater than the benefits. Aspirin use can result in stomach bleeding, bleeding in the brain, kidney failure, and some kinds of strokes.

What happens if you stop taking aspirin every day?

You might be surprised to learn that stopping daily aspirin therapy can have a rebound effect that may increase your risk of heart attack. If you have had a heart attack or a stent placed in one or more of your heart arteries, stopping daily aspirin therapy can lead to a life-threatening heart attack.

If you have been taking daily aspirin therapy and want to stop, it's important to talk to your doctor before making any changes. Suddenly stopping daily aspirin therapy could have a rebound effect that may trigger a blood clot.

What questions should I ask to learn about taking aspirin daily?

Before deciding if daily aspirin use is right for you, your health professional will need to consider:

- Can I use aspirin with other medicines, including prescription and over-the-counter?
- Can I use aspirin with other products, such as dietary supplements, including vitamins and herbals?
- Can I be allergic over overly sensitive to aspirin?
- What do I have to gain, or what are the benefits, from the use of aspirin?
• What side effects might I experience?
• What dose, and what directions for use are best for me?
• How would I know when the medicine is working or not working as it should?
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BIOGRAPHICAL SKETCH

Yulia A. Strekalova received a combined Bachelor of Arts/Master of Arts degree in political science and mass communication, graduating from the Russian State University for the Humanities. She also holds a Master of Business Administration Degree from the University of Florida Warrington College of Business. Since 2006, she has worked for the University of Florida in research management positions, managed administrative staff, and coordinated the submission of grant proposals. In Fall 2012, she entered the doctoral program in the College of Journalism and Communications continuing to work full-time as research administrator. During her graduate education, she has explored how information is disseminated and accessed through technology-mediated channels and how uncertainty about scientific evidence influences decision-making and behaviors. Strekalova’s research has been funded by the W. Martin Smith Interdisciplinary Patient Quality and Safety Awards Program and the University of Florida Clinical and Translational Science Institute. Strekalova has presented at numerous academic and professional national meetings, and her research has been published in Science Communication, Qualitative Health Research, Health Education & Behavior, Journal of Cancer Education, and Journal of Communication in Healthcare.