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BEYOND EXPOSURE: PATIENT ENGAGEMENT WITH HEALTH  
INFORMATION IN AN INFORMATION ECOLOGY FRAMEWORK

by

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And approved by

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## ABSTRACT OF THE DISSERTATION

Beyond Exposure: Patient Engagement with Health Information

in an Information Ecology Framework

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The traditional transmission model of communication continues to occupy a major portion of the current health communication research agenda, with the typical health communication application being the dissemination of well-crafted informational or persuasive messages through a mix of communication channels to a carefully selected target audience. However, systematic reviews of existing evidence suggest that the impact of this approach tends to be limited and modest at best because other forces, often more powerful, govern people's behaviors. This perspective, along with the increasingly merging areas of interpersonal and mediated communication, highlight a promising landscape advantageous for promoting or otherwise enabling healthier behaviors, positive outcomes, and lifestyles via a broader and more sophisticated range of human and mediated channels of health promotion and health delivery systems.

Considering the need for a revised approach, this project (1) outlines a conceptual model of patient engagement where individuals are considered self-determined agents navigating fluctuating levels of uncertainties and stimuli, (2) provides a conceptualization

of engagement as a communication-enabled mechanism that can facilitate the ability of individuals to achieve and maintain favorable health outcomes, and (3) conducts a preliminary empirical testing of select components of the model. The primary goal of the empirical study was to test a key assumption of the proposed model, namely that people are most likely to actively engage health information when they experience a triggering event or an event that crosses the threshold of uncertainty that they can tolerate.

Analyzing cross-sectional data from a nationally-representative sample of U.S. adults from the Pew Research Center's 2012 Tracking for Health Survey, findings suggest that there are statistically significant differences in patient engagement (information seeking, social support seeking, sharing) between those who report experiencing triggering stimuli versus those who report experiencing signaling stimuli. These findings have implications for the ways and critical periods patients can sufficiently activate engagement behaviors and sustain improved health outcomes.

*Keywords:* patient engagement, information-seeking, information sharing, social support, mobilization, mediated communication

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## DEDICATION

To my godmother and guardian angel, Hermelina Cotaco Enriquez

For always seeing the good in everything

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## CHAPTER 1

### INTRODUCTION

The communication and information environment that surrounds patients has changed radically over the past decade with the introduction of new media technologies and particularly the blurring of the traditional distinction between interpersonal and mediated health communication channels (Kreps, 2000). The old landscape was characterized by a relatively closed media system occupied by a handful of powerful actors (e.g., elite newspapers, network TV) with considerable control over the flow of information within the social system. The media and information landscape has since transformed, largely due to the evolution of media technologies and their affordances, toward an open and dynamic information system where people's limited role as consumers of information has been changing to encompass more active and engaged forms of interactions with information.

Now than any other time in the past, patients can actively and intently engage with information and with others (people, organizations, communities) over multiple communication platforms to advance their health-related goals (Baym, Zhang, & Lin, 2004; Quan-Hasse et al., 2002; Quan-Hasse, 2007). In addition, search engines and the ubiquity of Internet and mobile technology greatly facilitate patients' ability to seek and access relevant health information when they need it, from sources they trust, and in the format and frequency they prefer (Broadie et al., 2011; Wright, Sparks, & O'Hair, 2012). Finally, the networked individualism afforded by new media technologies greatly enhance the ability of patients to share health information with others and mobilize collective resources that can support personal and community well-being beyond the

information and resources available from traditional media and health care providers (Rainie & Wellman, 2012).

Health communication scholars have been increasingly occupied with describing and studying the effects of these changes on the delivery of health-related information and care to individuals and groups, noting the potential opportunities - but also challenges - to effective health communication in this new environment (see Wright, Sparks, & O'Hair, 2012 for a review). At the same time, there has been very little by way of reflecting on possible revisions to traditional approaches to health communication in light of these new developments. Specifically, existing models and applications of health communication, especially in the mediated communication domain, continue to almost exclusively draw on the rationale of the transmission model of communication (Shannon & Weaver, 1949) which emphasizes the production, dissemination, and reception of messages that promote positive health attitudes and behaviors among target audiences. This model necessarily invites a mostly linear view of health communication in which patients are assumed to be mere consumers of health information they receive (Carlsson, 2000; Leary, 1955). Beyond being criticized for its bias toward health information that is deliberately disseminated by institutional actors (Rule, 2002), there are good reasons to question whether exposure to such information can, by itself, produce health behavior change without buy-in from audiences (Daniel, Bernhardt, & Eroglu, 2009; Durkin, Biener, & Wakefield, 2009). Whereas a considerable body of research demonstrates a direct association between exposure to health information and changes in related cognitions such as attitudes, beliefs, and opinions (Lipinski & Witte, 1998), such information is often insufficient to motivate behavior change because it tends to compete



with powerful factors such as pervasive product marketing, social norms, and habits that act to sustain unhealthy lifestyles (Atkin & Wallack, 1990; Hornik, 1997; McGuire, 1986; Wakefield, Loken, & Hornik, 2010). Moreover, viewing the audience for health communication as consumers (informed as they may be) ignores audience members' personal agency and capability to seek and share information and other valued resources as well as regulate their own behavior (Bandura, 1996), a point I elaborate on next.

### **From Passive Consumer to Active Agents: Rethinking the Role of Patients**

The need to rethink the traditional conception of patients as consumers of health communication appears to be justified by a number of recent research insights. First, studies conducted by social psychologists (e.g., Campbell & Jovchelovitch, 2000; Noar, Benac, & Harris, 2007), behavioral economists (e.g., Bickel & Vuchinich; Glasgow et al., 2004; Thaler & Sustein, 2008) and even neuroscientists (e.g., Vohs & Baumeister, 2011) suggest that the traditional approaches to motivating health behavior change such as informing, educating, or incentivizing people are in many cases ineffective in today's saturated and stimuli-rich information environment where people increasingly rely on habits and automated responses to choose among alternative courses of actions. This emerging body of work suggests that in much the same way that habits shape and sustain human behaviors, they also determine people's communication and information behaviors. Accordingly, people may habitually ignore or dismiss preventive health information they receive, regardless of the source, channel, or message used to deliver this information, if they do not already have a reason to be concerned about their health (Weinstein, 1984). For all purposes, they treat such information as noise that distracts attention from the things they care about the most (e.g., their career or relationships).

However, once they are sufficiently concerned about their health status (or that of an important other), they appear to be quite motivated and capable to seek and use relevant health information on their own. Thus, if we accept the proposition that communication-based interventions have limited power to trigger (or cause) behavior change, we might more productively focus our attention on the ways people dynamically engage health information once they are triggered to act. Such focus would promote a shift towards more nonlinear, holistic, and dynamic explanations of information-seeking behavior (Foster, 2003).

Second, and in keeping with the issue of motivation to change, it is probably fair to argue that the majority of health communication interventions to date have been primarily designed to motivate people into initiating health behavior change. Trying to achieve this goal necessarily invites a strategy that is focused on changing salient cognitions such as behavioral beliefs, perceived efficacy and control, and perceptions of social norms as means to motivate people into behavior change. However, if we consider that most types of health-related behavior change involve a relatively long and complex process of behavioral modification (Prochaska & DiClemente, 1983), and that this process often requires people to effectively self-regulate or manage their behavior while coping with objective personal or environmental challenges that change dynamically (O'Neil & Drillings, 2012), it is unrealistic to expect that exposing individuals to health information be equally effective in stimulating health behavior change throughout the entire behavior change continuum (see also Schwarzer, 2008). Instead, it may be more productive to consider how communication mechanisms and processes help individuals *who are already motivated to achieve positive health outcomes* to obtain the help and

support they need to successfully navigate the objective constraints of their environment and to cope effectively with the challenges and setbacks they experience in the process of replacing old behavioral routines with new, healthier ones.

Indeed, viewing the role of communication in terms of facilitating people's ability to navigate health behavior change, as opposed to being the cause of that change, appears to be better aligned, conceptually, with the current emphasis on patient empowerment and the active role patients have in making decisions about their health (Feste & Anderson, 1995; Kreps, 2000). That is, the traditional transmission model of health communication mainly views patients as consumers of health-related information, thus equating an active patient with an informed one. In addition, patients are assumed to be active in this model to the extent that they are motivated to resist or counteract the message, either by selectively exposing themselves to information that confirms their predisposition or by processing the information in a biased manner. In contrast, a self-management-oriented model of health communication would expend patient activism beyond mere exposure to and processing of health information to include deliberate information-seeking and sharing behaviors (for example, in the context of online patient communities) as well as the deliberate production of health-related information (e.g., based on collecting and synthesizing personal or collective experiences) when such information is not yet available. Therefore, conceptualizing the role of health communication in this manner may have important advantages in terms of advancing both theory and practice in the field.

The third and final observation that motivates the current study is about the importance of considering the context in which people acquire, interpret, and use health-

related information. Many evaluations of communication-based interventions seek to isolate the contribution of health communication efforts to behavior change from that of other external factors by means of controlling or fixing their effects for all individuals either statically or by design (i.e., randomized experiments). However, in so doing, they often overlook the ways in which the characteristics of a person's information environment (or information ecology) can facilitate or impede the ability of this person to successfully navigate personal and/or externally-imposed challenges encountered in the process of behavior change (Altheide, 1995). Thus, in much the same way that a confluence of external or environmental factors that are beyond the control of individuals influence people's health-related behaviors (Daniel, Bernhardt, & Eroglu, 2009; Ramirez et al., 2002; Smedley & Syme, 2000), people's communication behaviors are too likely shaped by the characteristics of the information ecology in which individuals are embedded. In particular, it seems problematic to assume that all individuals have equal ability and opportunity to obtain and use relevant health-related information once they are motivated to do so when differential access to health information exists, not only due to the well-documented variations in personal resources, preferences, and competencies (Kreps, 2000), but also due to the objective condition such as the information technology infrastructure that is available in the communities in which people reside (Beaudoin, 2008; McMullan, 2006), as well as the limits (but also potential affordances) of their social network in terms of information flow and availability of social support (Brashers, Goldsmith, & Hsieh, 2006; Norris, 2001). Therefore, people's ability to pursue the health behavior change they desire critically depends on their ability to navigate successfully the health information ecology by actively and purposefully engaging public information

systems, health care providers, and their social networks to meet their evolving information and support needs.

Taken together, these emerging insights about patients' information and communication behaviors within an ever dynamic and complex health information environment merit a reconsideration of the role that patients now occupy in relation to health communication. In particular, these revelations seem to support a move away from the traditional view of patients as consumers of health information toward a conception of patients as active and self-determined agents who pursue health-related information and support within the affordances and limits of the information and social ecology and which they are embedded.

In the following chapter, I review the existing literature on patient engagement within the health communication field and then propose how the current conceptualization of this construct may be expanded to fit the conceptions of patients as active, self-determined agents who continuously engage (i.e., seek, share, and mobilize) their information and social environments to satisfy important informational and social support needs as they navigate the health challenges they experience. Next, I discuss the dynamic mechanisms and processes that cause or otherwise enable patient engagement and seek to situate this behavior in the broader context of the information and social ecology within which patients engage. Finally, I offer a conceptual model of patient engagement that fit this revised conception of the relationship between patients and health communication.

## CHAPTER 2

### RETHINKING PATIENT ENGAGEMENT

#### **Patient Engagement: An Overview**

A growing body of research suggests that patients who are more informed and actively involved in their health care tend to have better health care outcomes including enhanced patient care experiences, improved illness self-management, and lower health care costs (Barello, Graffigna, & Vegni, 2012; James, 2013). This has motivated additional research on the design, implementation, and evaluation of optimal patient education initiatives that can develop patients' knowledge, skills, abilities, and motivation to self-manage their health. Such interventions aim to increase engagement by “modifying patient medication compliance, chronic diseases self-management, and traditional behaviors associated with promoting health and preventing disease: smoking, diet and exercise” (Gruman et al., 2010, p. 354). However, the reliance on educational programs alone proved insufficient to narrow the gap in health outcomes (Pignone et al., 2005). Despite public and private health care organizations' efforts to educate and persuade patients to make informed health decisions, patients still struggle to understand basic health information and vary in the strength of their motivations, skills, and access to health resources. In response to this problem, patient engagement has progressively emerged as a critical area of study especially in the fields of medicine and nursing, but still lacks a shared definition across scientific communities (Barello et al., 2012).

#### **Definitions of Patient Engagement**

Patient engagement has various conceptualizations in the existing literature. James (2013) proposed that patient engagement ought to be treated as “a broader concept

that combines patient activation with interventions designed to increase activation and promote positive patient behavior, such as obtaining preventative care or exercising regularly” (p. 1). Still, Barello et al. (2012) note that patient engagement remains “a fragmented concept lacking a unique definition” (p. 4). Much of the difficulty of arriving at an agreed-upon definition of patient engagement appears to stem from the fact that current conceptions of the construct are limited to a particular dimension of engagement (i.e., cognitive, relational, or behavioral). References to patient engagement in the existing literature frequently treat engagement as a *cognitive* state that can greatly facilitate the accumulation of relevant health knowledge and the formation of accurate illness-related beliefs (Davis et al, 2005; Franklin et al., 2008). Meanwhile, other discussions of patient engagement emphasize the *relational* dimension of engagement such as a function of the frequency and quality of interactions between patients and health care providers (Simpson, 2004). Patient engagement has been also defined in terms of behavior (e.g., Casale et al., 2007; Lehman, Greener, & Simpson, 2002; Trotti et al., 2007). As a *behavioral* construct, patient engagement often involves actions such as question asking, active participation in treatment decisions, adherence to treatments, and the use of online tools for purposes like monitoring or safeguarding one’s health information (Hibbard et al., 2007; Lehman et al., 2002; McCracken, 2005). Gruman et al. (2010) define it as the “actions individuals must take to obtain the greatest benefit from the health care services available to them,” (p. 251). Furthermore, they classify engagement activities as serving individuals’ *health care* management goals (i.e., behaviors related to patient’s role in medical encounters or as the consumer-purchaser of health care services) and *health management* goals (i.e., behaviors related to disease

prevention, self-management). Hibbard et al. (2004), on the other hand, identify key behaviors indicative of attitudes and intentions towards engagement within an engagement behavior framework (EBF). Thus, the range of behaviors explicitly or implicitly expected of engaged patients remains underdeveloped in the literature (Gruman et al., 2010).

### **Approaches to Facilitating Patient Engagement**

Much of the attention given to patient engagement has focused on the clinical and organizational outcomes of engagement, rather than the theoretical, evidence-based investigation of the construct (Barello et al., 2012). In their review of the ten most cited articles published from 2002 to 2012 related to patient engagement, Barello et al. (2012) found that different authors approach patient engagement differently. For example, Carman et al. (2013) proposes a framework that positions engagement as an outcome of deliberate efforts by others to engage patients on a continuum ranging from a consultation model to a partnership model. Meanwhile, others may emphasize actions taken by patients themselves to engage with others about health-related matters (Lehman et al., 2002), whether physicians (Simpson, 2004), health care organizations (Villagra, 2004) or policymakers (Roy-Byrne & Wagner, 2004).

In general, four different (some may say, complementary) approaches to facilitating patient engagement co-exist in the literature on the topic. The *patient-focused approach* advocates shared decision-making and efforts to involve patients in their own clinical care emotionally, cognitively, and behaviorally (Barello et al., 2012). This approach emphasizes outcomes such as increased knowledge, better experiences of the illness and treatments, greater use of services, and lowered health care (Coulter & Ellis,



2007). It considers patients' preferences and clinical judgment as well as their health literacy and abilities to obtain, process, and communicate about basic health information (James, 2013). The 2001 Institute of Medicine report (IOM, 2001) called for this type of "patient-centered" reform in the health care system and emphasized the need to respect and respond to patient preferences, needs, and values in clinical decisions.

*A provider-focused approach*, on the other hand, looks at the roles of health care providers such as physicians, nurses, and family members in enabling or stimulating patient engagement. This approach considers the relational aspects of patient engagement and the extent to which the nature of the interaction between patients and providers produces efficient and reliable exchange of information and result in high-quality care for patients. Many studies between 2002 and 2005 in the mental health field cite this approach and conceptualize engagement as an alliance between patient and clinicians to promote treatment effectiveness (Barello et al., 2012). By building partnerships with patients and their families, providers can develop appropriate health management plans and meaningful discharge goals that promote their engagement (Grant & Colello, 2009). Many studies that adopt this orientation describe the challenges and opportunities in shared decision making, but also highlight how patients may opt for less invasive and expensive treatment plans against doctors' recommendations or the ways physicians may be reluctant to relinquish their traditional decision-making roles (see Dentzer, 2013 for review).

Another approach to patient engagement is the *organization-focused approach* that looks at the core organizational components related to achieving optimal care such as care coordination, the continuity of care, and the processes of health information

exchange (Barello et al., 2012). Effective organizational processes can improve disease management, increased patient satisfaction, and effective patient-provider relationship outcomes (Cahill, 1998). In this type of approach, the emphasis is on engagement as a measurable marker of clinical effectiveness contributing to reduced health care costs (Villagra, 2004). It also emphasizes applying evidence-based knowledge about health care systematically and expeditiously in clinical practice (Institute of Medicine, 2001).

Finally, improvements made in health care require the participation of not just consumers but federal and state policy members, public and private purchasers of care, regulators, and governing boards. Thus, some advocates for increased patient engagement also mention a *policy-focused approach* and refer to the elements in health policy making that contribute to the effective delivery of high quality healthcare interventions (Roy-Byrne & Wagner, 2004). Such efforts include the creation and dissemination of specific practice guidelines to clinicians and the general public, the identification of best practice processes, and the development of quality care assessment measures (Institute of Medicine, 2001). A commitment to core patient needs rooted in policy can hold health care constituencies accountable for meeting patient needs and providing safer, more reliable, and more available health care services.

### **Patient Engagement as Self-Determined Action**

The current literature on patient engagement offers ample evidence that patients can and are actively involved with decisions about their health, seeking or “extracting” health information from health care providers, media outlets, and others in their social network (Carlsson, 2000; Feste & Anderson, 1995; Hesse et al., 2005; Ramirez et al., 2002). As noted above, this evidence seems to fundamentally challenge the view of

patients as mere consumers of health information, which is a core assumption of the transmission model of health communication. That is, in an information transmission framework, onus is placed on the public health system and health care providers to “push” or provide audiences with the knowledge, skills, and motivations to engage in behavior change because people are assumed to lack the motivation and/or capacity to engage in health behavior change. This has led health communication scholars to focus their attention on communicating such information in engaging ways so to stimulate patients’ interest and motivation to pursue the recommended change. However, they may approach their task differently if they assume instead that people are already motivated and capable to seek, find, interpret, and use health information on their own.

Theoretically, such proposition can be derived from the rationale of self-determination theory (SDT) and its emphasis on human agency. According to SDT (Deci & Ryan, 2002), people are inherently proactive beings with direct agency over their inner forces (e.g., personal drives and emotions) and a natural tendency toward optimizing their inherent growth and functioning. However, optimal development also depends on the degree to which one’s social-contextual conditions facilitate (as opposed to suppress) the natural processes of self-motivation, psychological development, and personal well-being (Deci & Ryan, 1985; Ryan, 1995). Thus, people continuously engage their environment as they strive to fulfill three universal psychological needs – competence (Harter, 1978; White, 1963), relatedness (or the desire for interaction, connection, and caring, see Baumeister & Leary, 1995), and autonomy (deCharms, 1968; Deci, 1975) – that are needed for optimized self-determination, personality development, and behavioral self-regulation (Ryan & Deci, 2000). Importantly, when these needs are satisfied, they

contribute to optimal functioning for growth and integration, however, when needs are unmet (or some needs are more fulfilled than others), people are capable and motivated to actively seek means for satisfying these needs by engaging other entities (institutions, organizations, other people) in their environments (Ryan & Deci, 2000). Thus, self-determination is critical to the process of behavior change: without self-determination people cannot cope effectively with the challenges (including illness-related challenges) they experience as they pursue their personal goals. Previous research suggests that even when perceived behavioral control and intentions to achieve behavior change are present, they are sometimes not enough to address issues of action implementation (Johnston et al., 2004).

In his agentic theory of human behavior, Bandura (2001) proposes that self-determination has also important implications regarding the environment in which people are embedded. According to this theory, humans are individuals capable of agentic action who can explore, manipulate, and influence their environment as they pursue the gratification of their needs. The human mind is not just reactive, but generative, proactive, and reflective and “people are not just onlooking hosts of internal mechanisms orchestrated by environmental events. They are agents of experiences rather than simply undergoers of experiences” (Bandura, 2001, p. 4). This perspective, similar to SDT, suggests that although people operate within social-contextual conditions, they are not limited by the constraints of this environment to determine their behavior. People are likely to take action when the perceived benefits of performing the behavior outweigh the perceived costs or negative consequences of the behavior, they believe they possess the skills and abilities necessary for performing the behavior, and have a sense of personal

agency (Bandura, 1986). Self-determination is an inherent motivation of human actors that, once triggered by the desire to fulfill urgent or salient needs, naturally pushes people to actively engage (explore, manipulate, or influence) their environment. Hence, both SDT (Deci & Ryan, 2002) and social cognitive theory (Bandura, 1986) strongly suggest that meaningful and lasting behavior change can only be achieved through self-regulation (as opposed to external or social regulation of behavior through the use of incentives or sanctions), and that self-determination (i.e., the ability to set and pursue personal goals) is a crucial component of self-regulation.

In subscribing to this theoretical rationale, I seek to further position patient engagement as a self-determined behavior that takes place within the information and social environments in which patients are embedded. My goal is to propose a model of patient engagement with health communication that augments (as opposed to replaces) the traditional transmission approach to patient engagement. In what follows, I first attempt to expand the current definition of patient engagement to include a host of purposive information and communication-related actions that can support individuals' ability to navigate personal health challenges and/or cope with illness. Next, I offer a theoretical framework that links patient engagement to its behavioral antecedents and outcomes as well as to the larger environment or ecology in which individuals enact this behavior. I then focus specifically on the question of when and how self-determined patient engagement is activated, introducing the idea of behavioral triggers and their relation to uncertainty, and deriving the study hypotheses.

## CHAPTER 3

### THE CONCEPTUAL FRAMEWORK

#### Explication of Patient Engagement

In this study, I define patient engagement as *deliberate actions individuals take to seek, share, and/or mobilize information and other forms of support from social systems or actors in their environment in order to prevent, manage, and cure illness*. This definition reflects three crucial assumptions about the nature of patient engagement. First, while the construct “engagement” is frequently used to mean the state of being engaged (i.e., being attentive and highly-involved with a particular stimulus or task), engagement as it is defined here refers to the act of engaging, or the deliberate actions people take to obtain something they need from systems or others in their environment. Because “engagement” implies the active, conscious, and self-determined pursuit of information and other valuable resources, it portrays a more active form of audience involvement relative to “exposure” as it is used in the traditional transmission model. This definition further assumes that patient engagement is placed on a continuum in which individuals continuously engage with systems and with other individuals to prevent, manage and cure health issues they experience, but that the degree, intensity, and content of engagement vary dynamically as a function of their needs, preferences, health circumstances, and abilities.

The second crucial assumption made here is that patient engagement inherently involves communicative acts. That is, one necessarily relies on interactions to engage systems and other social actors in an effort to satisfy ongoing or emerging information, psychological, social, and instrumental needs (see also Prochaska, Redding, & Evers,

2008). Because the “other” is implicated in these actions, engagement actually encompasses much more than information transfer; it also includes the exchange and mobilization of information and resources by means of connecting with others. Since engagement is assumed to be a behavior, we can offer a more refined definition of engagement based on the theory of reasoned action’s target-action-context-time (TACT) framework (Fishbein & Ajzen, 1975): (1) target of engagement (systems or people), (2) the engagement-related action involved (seeking, sharing, or mobilizing), (3) the context or intended objective of engagement (acquire information or a particular type of social support), and (4) timing of engagement (the regularity or frequency in which the action is repeated). For example, a form of engagement occurs when a patient goes to an online forum (target) to seek health information (action) about a cancer treatment (context) after each doctor’s appointment (timing). Note that explicating the construct in this manner intentionally leaves out the dimension of quality and intensity of engagement (e.g., Ellison, Steinfield, & Lampe, 2007), which is frequently used to assess engagement as a state (e.g., level of attention, degree of arousal, amount of cognitive processing, etc.), but is not appropriate here since assessing the quality of efforts to engage elements in one’s environment necessarily invites reference to their overall efficacy in accomplishing the task. This is not to say that possessing certain abilities or competencies (e.g., advanced information seeking skills or the ability to adapt to your communication partner) is not important in this context. Clearly, some individuals can perform these tasks faster and better as a function of their ability and skills. The point is that skills and competencies *enable* people to accomplish the goal of engaging (e.g., the likelihood that they will find the information they search for) but are not the act of engaging per se.

The third important assumption underlying the definition of patient engagement that I offer here is that engagement, as a behavior, must be understood in the context in which it is embedded, specifically, in relation to the information and social ecology in which patients engage other actors. Whereas ‘ecology’ in the general sense refers to the interactions of organisms or entities within their environments (Altheide, 1994, 1995; Sallis & Owen, 2002), a socio-informational ecology more specifically involves interactions that connect actors (whether individual or social) to information and other desired resources available from social systems (i.e., information and media systems, health care system, political and legal system, and community institutions) as well as from other actors in one’s social network such as physicians, family members, friends, coworkers, and support groups. Such interactions not only condition (i.e., facilitate or impede) the ability of patients to actively engage with their environment but also motivate patient engagement. That is, a crucial assumption of my conceptual model is that patients are motivated to engage social systems and people in their environment to cope with and navigate objective or external barriers in their environment that impede their progress toward achieving their goals.

### **Dimensions of Patient Engagement**

The definition of patient engagement used in this study is very much aligned with previous work that has used information and support seeking behaviors to operationalize patient engagement with health information or resources (for an overview, see Anker et al., 2011). For example, previous studies have already considered behaviors such as scanning or seeking information from publicly available online sources (Niederdeppe et al., 2007) and from online patient communities (Ancker et al., 2009; Fox, 2010; Radin,



2006). However, this emphasis on seeking behavior ignores two additional important behaviors that define patient engagement in reality: sharing and mobilizing. *Sharing* behaviors in this study focus specifically on interactions meant to benefit others' information and support needs (although there may be benefits to oneself and the relationship), such as when patients offer advice or encouragement to other patients or refer them to useful resources that can help them solve a personal problem they encounter. For online interactions, examples of sharing behaviors include posting a review about a doctor or treatment plan. *Mobilizing* behaviors refer to patients actively lobbying social systems or other patients to engage in collective action that can benefit the group as a whole such as crowdsourcing (collecting and integrating personal experience to produce a collective account of typical experience) and advocacy efforts (e.g., petitioning officials, demanding additional resources to fight a particular disease, etc.). An example of mobilizing includes a patient who, at first, is unsuccessful in locating information on a rare combination of drugs and illness conditions but later leverages the knowledge of other patients to collectively curate and create the needed content.

**Information-Seeking as engagement.** Health information-seeking has been typically considered in relation to uncertainty-management (Mishel, 1988). In general, the literature suggests that the pursuit of information or any “stimuli from a person’s environment that contributes to his or her knowledge or belief” (Brashers et al., 2002, p. 259) can improve one’s ability to cope and understand procedures during diagnosis, treatment, and post-treatment stages (e.g., Cawley et al., 1990; Garvin, Huston, & Baker, 1992; Luker et al., 1995), can benefit a relative or friend (Fox & Fallows, 2003), increase

satisfaction with health choices, reduce anxiety (e.g., Afifi & Weiner, 2004; Brashers et al., 2002), and lead to better interpersonal communication and outcomes (e.g., Reynolds et al., 1998; Rutten et al., 2005). The desired types of information are often related to patients' procedural ("What will happen to me?"), sensory ("How will it make me feel?"), and prevention and risk concerns to help patients cope with health stressors (Garvin et al., 1992).

Accordingly, information seeking has been conceptualized as a "goal-driven activity" (Ramirez et al., 2002, p. 217) and an active and purposeful process beyond incidental and mere exposure (e.g., Hornik, 2002; Shapiro, 1999), casual seeking, and browsing (e.g., Dutta-Bergman, 2004). Unlike *information scanning*, which involves "routine patterns of exposure to mediated and interpersonal sources that can be recalled with a minimal prompt" (Niederdeppe, 2007, p. 154), *information-seeking* involves deliberate and active efforts to obtain specific information outside of the normal patterns of exposure about a target (Atkin, 1973; Griffin et al., 1999; Ramirez et al., 2002). Because I characterize engagement as a self-determined act, I am interested in the behavior of those patients who are highly intent, aware, and self-motivated to pursue knowledge, facts, and understanding of the circumstances related to their health.

Accordingly, information seeking behavior can be placed on a continuum ranging from passive, accidental exposure to deliberate, active pursuit of information (Berger, 2002).

Information-seeking is also often characterized by the source (interpersonal or mediated) through which the process undergoes (Cline & Haynes, 2001; Lenz, 1984). Although people increasingly use the Internet for health information, many patients turn to their interpersonal networks to obtain the information they desire. Patients often

consult family, friends, and other members of their support network about their own knowledge and experiences regarding disease, prognosis, and treatment options (Brashers et al., 2002) and many prefer doctors, pharmacists, and nurses as their primary sources of health information (Leung, 2008). Supportive others serve as collaborators, evaluators, and brokers in information gathering and buffering strategies (Brashers et al., 2000; Miller & Zook, 1997). In the case of HIV and AIDS patients, for instance, health care providers and physicians provided valuable information for patients' home care, symptom management, and general advocacy (Miller & Zook, 1997).

Information communication technologies (ICTs) such as Internet-enabled mobile phones and computers are also preferred sources to access updated, expert information such as that found on government health sites, electronic medical journals, and sites for credible professional medical organizations like the American Psychological Association and the American Medical Association (see Morahan-Martin, 2004 for review). Worldwide, about 4.5% of all searches on the Internet are for health-related information purposes (Eysenbach & Kohler, 2003), and about 93 million Internet users in the United States are considered "health seekers" who have sought out health information online (Madden, 2003; Fox & Raine, 2001; Fox & Raine, 2002). ICTs can serve informational needs by providing awareness and knowledge, instrumental needs by enabling courses of action, communal needs by bringing people together, and social control needs by legitimizing certain health behaviors (Viswanath, 2006). Online health information allows people to feel more empowered in their personal health-making decisions, be more proactive in their uses of information, and obtain convenient, around-the-clock access to support groups (Fox & Raine, 2002; Rice & Katz, 2001; Sharf, 1997). Patients

may also choose social support obtained through computer-mediated communication channels over parallel face-to-face interactions for a number of reasons, including rewarding hyperpersonal exchanges, more flexibility in physical location, and the ability to selectively self-present and edit (Walther, 1996).

Robinson et al. (1998) refers to mediated information-seeking as “interactive health communication,” where an individual (consumer, patient, caregiver or professional) “interacts with or through an electronic device or communication technology to access or transmit health information or to receive guidance and support on a health-related issue” (p. 1264). Patients sometimes seek informational support this way because it may be otherwise low or missing within their lives. For example, Turner, Grube, and Meyers (2001) found that a low degree of face-to-face support available in a patient’s life was associated with more reading of a health-related listserv and a meeting of list members in a private email. This suggests that patients may actively seek out online options for information in addition to or perhaps in place of their interpersonal ones.

**Social Support-Seeking as engagement.** Uncontrollable events especially life-threatening ones often drive people to seek emotional and other forms of social support that can help short and long-term coping with adverse health events (Cutrona & Russell, 1990). Accordingly, patients may have needs that can only be fulfilled directly or indirectly by the communication of help and encouragement exchanged with another person (Goldsmith, 2004). Therefore, social support functions to let people know there is care, love, esteem, and value available for them (Cobb, 1976). With its roots in the mental health literature (Caplan, 1974; Cobb, 1976), social support later evolved to

capture “an exchange of resources between at least two individuals perceived by the provider or the recipient to be intended to enhance the well-being of the recipient” (Shumaker & Brownell, 1984, p. 13), with either a negative or positive effect (Cohen & Syme, 1985), and a “perceived or actual instrumental and/or expressive provisions supplied by the community, social networks, and confiding partners” (Lin, 1986, p. 18).

Social support was originally characterized by five key dimensions: (1) *direction* (support given or received), (2) *disposition* (availability vs. utilization of support resources), (3) *description* of support versus *evaluation* of satisfaction with support, (4) *content* (form the support takes shape), and (5) *network* (the social systems that provide support) (Tardy, 1985). For the purposes of this project, the focus is on the *seeking* of social support and not on its *provision* or *reception* (see Goldsmith, 2004 for review), and the pursuit of support in one’s network (ecology) as a response to one’s uncertainty discrepancies. Sometimes referred to as “help-seeking,” the process of support seeking refers to patients aiming to fulfill tangible, psychological, or social needs required for coping effectively with their health condition (Cohen & Wills, 1985; Goldsmith, 2004; Sanford, 2010). Social support seeking indicates an interactive process with one’s social ecology in which patients cognitively appraise their support options and then pursue “support, advice, or assistance in times of distress” including both general discussions about problems and specific appeals for aids from friends, relatives, and professionals (Gourash, 1978, p. 414). Venting, although not traditionally in the category of social support seeking, is worth mentioning because it may be affiliated with “sharing” activities. Venting involves emotional expressions that have been associated with lower

social integration, more self-blame, and higher dissatisfaction and closeness with online and offline friends (Baker & Moore, 2008; Pennebaker et al., 1990).

Several types of and benefits to social support are described in the literature, including emotional (e.g., affection, trust, nurturance), informational (e.g., advice, guidance, explanations for the illness), tangible (e.g., financial or material assistance), intangible (e.g., personal advice), companionship (e.g., sense of belonging), and esteem (e.g., positive evaluations of identity or self) (Albrecht & Adelman, 1987; Aldwin & Revenson, 1987; Burleson & Samter, 1990; Cobb, 1976; Cutrona & Suhr, 1994; Folkman & Lazarus, 1985; Holmstrom & Burleson, 2011; MacGeorge, Feng, & Burleson, 2011; Weisz & Wood, 2005; Wills, 1985). Online support communities, especially those found in social media, can provide escape from the responsibilities and pressures of a diagnosis, entertainment, affection, and social information (Quan-Haase & Young, 2010) as well as limited-cue environments for people to obtain whichever type of support they need when the depth and support they receive from the specific persons in their lives is low (Turner, Grube, & Meyers, 2001).

The reception of social support has been linked to benefits such as improved coping, lower stress, and less psychological distress (Lopez & Cooper, 2011). It has also been found to enable a person to reduce uncertainty and collaborate with others to evaluate and buffer information (Brashers et al., 2004; Cohen & Wills, 1985; Goldsmith, 2004). Additionally, the social support-seeking process itself provides beneficial degrees of cognitive processing, heuristics and sensation inducements, and propels the recipient's processing ability (Burleson, 2009b). Even the mere perception of available social support can reduce stress, enhance confidence, and improve one's health and adjustment

(Cohen, Gottlieb, & Underwood, 2000). Compared to information-seeking behaviors, people who are seeking support or help are usually in search of comfort, reassurance, and advice (Gurin et al., 1960; Rosenblatt & Mayer, 1972). Social support also facilitates beneficial identification processes, where others experiencing similar treatments can also provide patients with a “buffer” or protection against the negative effects of uncertainty and stress-inducing events (Cutrona & Russell, 1990). In this regard, social support and the pursuit of it can facilitate a person’s coping and have an overall beneficial effect on the recipient’s well-being (Cassel, 1976; Cobb, 1976).

**Sharing as engagement.** Health information sharing is another form of patient engagement, involving the extent to which patients publically or privately contribute knowledge, opinions, relevant experiences, and advice for the sole purpose of benefiting others and without expectation of reciprocity. The Internet and social media platforms especially facilitate information sharing by providing a community space for common interests to be sought and shared, unconstrained by space and time limitations (Baym, 1997; Sproull & Kiesler, 1991; Wellman, 2001). Sharing is distinct from information and social support seeking because it involves patients contributing to rather than withdrawing information or other resources from other actors they interact with within the same information and social ecologies. Additionally, sharing is typically in a public forum, not grounded in specific relationships, and does not involve the anticipation of reciprocity from others. Sometimes referred to as “knowledge sharing” (van de Hooff & De Ridder, 2004), sharing typically involves an interpersonal “behavior of disseminating one’s acquired knowledge to other members” (Ryu, Ho, & Han, 2003, p. 113) both

within and outside formal organizations<sup>1</sup>. Sharing allows participants to demonstrate common functions and to learn from, contribute to, and build upon a collective knowledgebase. In other words, sharing is inherently an altruistic behavior (Ancker et al., 2009). In many cases, patients may choose to publicly share information without knowing who or if a recipient exists. Virtual spaces such as “social awareness streams” in popular social media platforms like Facebook and Twitter (Naaman et al., 2008) allow people to share content with a “perceived audience” (Boyd, 2008). Even if members of the audience are not truly known by the message sender (e.g., when a message or “post” is publicly available), he or she can contribute health-information to benefit and maintain the norms of the online community (Newman et al., 2011; Sanford, 2010; Teodoro & Naaman, 2013). When sharing occurs, the contributions of personal experiences, learned information, or recommendations given in a communal space are free for supply, use, and distribution without any immediate costs to the recipients.

According to a study by Van den Hooff and de Ridder (2004), the more knowledge a person collected, the more he or she was willing to donate knowledge to others as well, and a constructive communication climate positively influenced knowledge donating, knowledge collecting, and affective commitment. Patients who share information with others are therefore considered highly engaged since patients must overcome their uncertainties about a health condition in order to perceive an ability to share (Checton et al., 2012) and it involves a considerable amount of effort to craft, tailor, and distribute learned information.

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<sup>1</sup> Conceptually, sharing is different from self-disclosure because it lacks an inherent expectation of matching among interactants in terms of breadth, depth, and increased intimacy (Defenbaugh, 2013; Greene, Derlega, & Matthews, 2006; Omarzu, 2000).



Although patients frequently share health information with other patients in face-to-face conversation, sharing is increasingly taking place through online or virtual communities (Hsu et al., 2007). For example, health information systems such as PatientsLikeMe ([www.patientslikeme.com](http://www.patientslikeme.com)) support the collection, analysis, and critique of patients' personal and peer data. Such communities promote knowledge, discussion, and health care utilization to greatly benefit patients as the primary stakeholders of their health (Frost & Massagli, 2008). Other studies have found that making contributions to online communities can support effective action and prevent relapse in the behavior change process (Scharefel et al., 2009).

There are of course some concerns patients have about sharing health information over electronic information systems. They consider or anticipate the possible identity of the recipient (respondents were most willing to share information with healthcare professionals), the level of anonymity (respondents were more prepared to share anonymously than with their identities tied to their personal information), and the type of information shared (respondents felt sharing information was more personal in nature and were therefore more unwilling to share) (Whiddett et al., 2006). People also naturally tend to hoard information for themselves and are skeptical of information shared by others (Davenport & Prusak, 1998). However, sharing can “facilitate coping with illness uncertainty, interference, and the complexities and unpredictability of managing the condition” (Checton et al., 2012, p. 118). By sharing, patients may validate their sense of self-worth by supporting others as active producers and not just consumers of knowledge and experience (Burlison & Samter, 1990; Cobb, 1976; Cutrona & Suhr, 1994; Holmstrom & Burlison, 2011; MacGeorge, Feng, & Burlison, 2011). Sharing has been

described as a “cathartic” experience where individuals can discuss wins, challenges, and struggles (Sanford, 2010) and relieve their distress (Afifi & Steuber, 2009), which can therapeutically benefit and foster the development of positive self-concepts (Chung & Kim, 2008).

**Mobilization as engagement.** Another form of engagement involves the ways people rally others in their environment into collective action for the purposes of mobilizing collective information and knowledge as well as other resources. Some refer to a limited conceptualization of mobilization known as “knowledge mobilization” or “the act of moving research results into the hands of research users” (Gainforth et al., 2014, p. 1). In this knowledge-into-practice approach, those who are more interpersonally connected are at a distinct advantage for a greater diffusion of innovations. Others refer to mobilization as a form of connective action in which communication serves as the organizational process that brings diverse individuals sometimes from dispersed physical groups together to channel resources and create loose ties to address today’s problems (Bennett & Segerberg, 2013). Schiavo (2013) describes “community mobilization” in a similar fashion, “By using multiple communication channels, community mobilization seeks to involve community leaders and the community at large in addressing a health issue, becoming part of the key steps to behavioral or social change, or practicing a desired behavior” (p. 25). It is a bottom-up, participatory approach that empowers individuals to advocate for changes that cultivate environments receptive to the development of health services, political involvement and commitment, and raising awareness and funds for medical services and scientific discoveries. Engagement through mobilization positions ordinary people as the agents of

change, where individuals “find their own solutions, whether or not the problem is solved” and often involve local leaders and other levels of society such as governments and professional organizations (Fishbein, Goldberg, & Middlestadt, 1997, p. 294).

Essentially, mobilization captures the ways patients use communication to “crowdsource” information and other resources by collecting, generating, or collaborating on knowledge that does not currently exist – and use it to motivate others to participate in collective action. Of the types of engagement described in this study, mobilization compared to the others can be a lengthier and more high commitment process. It often involves bringing together community partners to raise awareness, demand, and progress for a given disease or health condition for the purpose of achieving progress an initiatives goals and outcomes (Patel, 2005).

### **Determinants of Patient Engagement**

Patient engagement in this study is conceptualized as the information and communication behaviors patients enact to interact with systems or people in their information and social environment for the purpose of obtaining the information and other resources they need to prevent, manage, or overcome illness. Following the COM-B framework (Michie, van Stralen, & West, 2011), the form and degree to which patients engage their environment are assumed to be a function of their motivation, capability, and opportunity to engage. The unique combination of these factors can explain variations in engagement across patients as well as for the same patient over time. *Capability* generally refers to a person’s actual ability, knowledge, or skills to act on, gain access to, or follow-through with a target behavior. *Opportunity* refers to objective personal circumstances (e.g., time, money, access to internet, etc.) and/or external

arrangements (e.g., availability of certain services or health care professionals, community's social capital, etc.) that are beyond the control of the individual and that can facilitate or impede engagement, either directly or indirectly (Berkman & Kawachi, 2000; Viswanath, 2006). *Motivation* is the driver of engagement and is based on a person's desire to satisfy needs, achieve personal goals, and/or act in a self-serving manner. However, it can also be based on the desire to support or assist another person.

Additionally, the factors of capacity, opportunity, and motivation collectively provide a lens to better understand the impact of health determinants such as general inequality, poverty, and a lack of access to social and technological support on engagement. Below I offer a more specific discussion of each of these three determinants of patient engagement as defined in this study.

### **Patient Engagement Capabilities**

Patients' ability to engage the systems and/or people they interact with is contingent upon their mental and cognitive capacity as well as the communication or information-related competencies and skills needed to initiate successful interactions with other individuals or with human-made systems (Michie, van Stralen, & West, 2011; Spitzberg, 1993 (Wiemann & Backland, 1980). Ramirez et al. (2002), for example, refer to capability factors as "communicator-related" factors based on personal background or history (e.g., personality characteristics, skills, and preferences), which can influence engagement or information-seeking strategies. Computer literacy and online fluency, for example, were found to contribute to differences in information seeking and access to information among different segments of the population (Bunz, 2004; Hargittai & Hinnant, 2008). Accordingly, as patients' needs become more focused, urgent, or salient,

their ability to effectively determine who or what to engage, how, and with what intensity can influence their progress towards improved health status (Kreuter & Wray, 2003; Marton, 2003). Patients' acquisition and evaluation skills are thus critical factors in determining how health information is retrieved, evaluated, and used. For example, most users of online health information utilize general search engines like Google to locate information about specific medical conditions or diagnoses. However, this is typically associated with problematic practices including the entering of short, often misspelled phrases, a lack of attention to credibility indicators, and a limited exposure to information beyond the first page (Morahan-Martin, 2004). Having the abilities to demonstrate selectivity and discretion when it comes to deciding amongst competing informational and social sources can aid in the interpretation of medical information and potentially prevent misunderstandings, incorrect expectations regarding treatments, and information inapplicable to their own conditions. Indeed, individuals facing inequality and poverty may be at disadvantageous positions for acquiring and developing their capabilities for engagement. They may lack core competencies for seeking information, seeking social support, sharing information, or mobilizing their community. Capabilities have also been linked to increased relational satisfaction and social support (Albrecht & Adelman, 1987; Apker, Ford, & Fox, 2003; Query & Wright, 2003).

Important to note is the difference between actual patient capacity versus perceived patient capacity (or efficacy). Although patients may have strong "communication efficacy" or confidence in their abilities to communicate about some kind or type of information with their health care providers and referent others (Afifi & Weiner, 2004), this does not mean they have the actual abilities to communicate

effectively. In the same vein, perceived self-efficacy – although this construct has been attributed to the perseverance over challenges (Maibach & Murphy, 1995) – describes one’s *perceived* ability to exert personal control in pursuit of behavior change (Bandura, 1977). Again, this perception may differ from the actual capability to navigate health information due to objective barriers such as poor language skills, limited formal education, and lack of experience maintaining healthy behaviors (Neuhauser et al., 2008).

Patients who demonstrate strong abilities and communication skills to acquire health knowledge and readjust their usual behavior patterns in response to changing uncertainties derived from environmental, social, or internal demands are generally better equipped to prevent complications, apply appropriate treatments, and cope with potential barriers or challenges (Holman & Lorig, 2000; Holmes & Rahe, 1967). For example, research conducted by Cegala et al. (2000) found that trained patients who were instructed about information provision, information seeking, and information verifying prior to a scheduled appointment demonstrated more joint participation and decision-making in regards to their health care. They asked “significantly more direct, assertive, and clarifying questions about their current problem” and provided more detailed elaboration on questions asked by physicians than patients who were just informed immediately before their appointment or did not receive any training at all (Cegala et al., 2000, p. 219). By comparison, patients who are less skilled in eliciting information from their physicians are likely to request health information indirectly and become frustrated and uncertain about their illnesses and treatments (Weijts et al., 1993). Compared to less educated patients, younger and more educated patients received more information during consultations due to their less passive communication styles and doctors’ misjudgment of

their information needs and desires (Street, 1991). These studies suggest that the *skills* for executing engagement behaviors, in this case enabling improved patient participation and communication skills can have an effect on the physician-patient communication exchange and measurably better health outcomes (Kaplan et al., 1996).

Patient capabilities also involve the fundamental “ability to read, understand, and act on health information” (Andrus & Roth, 2002, p. 283). Also referred to as “functional health literacy,” it involves tasks such as “reading and comprehending prescription labels, interpreting appointment slips, completing health insurance forms, following instructions for diagnostic tests, and understanding other essential health-related materials required to adequately function as a patient” (Andrus & Roth, 2002, p. 283). Compared to those with high health literacy, patients with low health literacy have higher hospital admission rates, are more likely to commit drug and treatment errors, and make less use of preventative resources and services (Institute of Medicine, 2004). In addition, health literacy skills help individuals recognize and distinguish a reliable, valuable source from an untrustworthy, questionable one (Eysenbach & Diepgen, 1999). Even with credible sources providing quality health information, content may be written in technical language, which patients may lack the skills to decipher. As a result, this may increase rather than decrease their uncertainties about their illness and treatment options (Berland et al., 2001). Therefore, Internet users’ capabilities to navigate sensitive health topics (Renahy & Chauvin, 2006) and assess information quality and credibility (Fox & Fallows, 2003) can affect the extent patients engage with their information ecologies.

### **Patient Engagement Opportunities**

Individuals' opportunities, or lack thereof, to obtain information and interact with human and technological resources are also presumed to determine the form and degree of patient engagement. The availability of and ease to which patients can access resource-endowed social actors and systems in their environment, especially in the age of an Internet-connected society, can consequentially impact the extent to which they seek information, locate others who can help or are like them, and share their experiences. Beyond constraints posed by the objective reality of one's environment (e.g., community size and resources), opportunities to engage with others are strongly associated with social capital, both at the individual and community levels. At the community-level, social capital can facilitate forms of collective action that can effectively promote solutions to public problems by facilitating trust, cooperation, binding norms, and commitment to action among members of the community (Coleman, 1988; Coleman, 1990; Newton, 1997; Putnam et al., 1993). And although having high social capital is generally considered positive for engagement (there is arguably a burden in having a high social capital), on its own the opportunities afforded by varying levels of social capital overlook individual agency to alter or create new experiences. At the individual-level, social capital can vary depending on the information and resources patients can access through their interpersonal contacts. The differences in patients' interpersonal network composition, structure, and available resources can create unique pathways, which may (a) influence the diffusion of and exposure to health-related information, norms, and overall adoption of healthy behaviors, and (b) affect access to services and amenities that promote socially cohesive communities and security of its members (Kawachi & Berkman, 1998; Veenstra, 2000).



Opportunity to engage is also a function of access. Thus, despite the steady rise of Internet access in America (Pew Internet & American, 2006) and with almost 80% of Internet users searching for health information online (Fox, 2006; Hampton, Goulet, & Rainie, 2011; Hesse et al., 2005; Sarasohn-Kahn, 2008), studies still find an ongoing gap of access between the information “haves” and “have-nots” (Jennings & Zeitner, 2003; Norris, 2001). This fuels the “digital divide” debate, where people differ in their opportunities and access to information, connections to ICTs, and interactions with people behind the ICTs. Given that information ecologies differ from patient to patient, their opportunities for information and resources can also vary in terms of breadth (size and magnitude of access to information systems and personal networks), quality (composition of mediated and interpersonal resources), relevance (needed vs. excess resources), and timeliness depending on the constraints of their information ecologies.

The first barrier, the *lack of access to elementary digital experiences*, recognizes that merely providing a person with digital or computer-mediated technology does not solve information inequality. There may be differing trust and concerns with Internet information, confidentiality, and cultural biases contributing to non-use (Brodie et al., 2000). Often overlooked are the “mental barriers” or personal insecurities caused by negative attitudes or computer anxiety associated with use, a lack of interest in the latest technology, and the unattractiveness of learning new technology among populations who did not grow up with (e.g., “digital natives” vs. “digital immigrants”) or care to locate opportunities to experience or learn the technology (and therefore reap the benefits of engagement with it) such as the elderly, illiterates, and the unemployed (van Dijk & Hacker, 2003).

The second barrier refers to having a *lack of material or physical access to computers and network connections*. Opportunities to possess or access a computer and connection are especially important because people can alleviate their uncertainty discrepancies by tapping into a range of informational and interpersonal resources when and where they need it. However, the possession of material or physical access to computers and network connections are contingent on a number of social categories such as income, education, occupation, age, gender, ethnicity, and geographic location, with the gaps in access seemingly widening for all categories except gender (Brantgarde, 1983; Hargittai & Hinnant, 2008; Lee, 2009; van Dijk & Hacker, 2003; U.S. Census Bureau, 1984, 1997, 2000; Wanta & Elliott, 1995). The lack of available services or health care professionals in one's immediate community or social networks can also have a direct or indirect impact on the extent to which a patient engages with his or her ecology (Berkman & Kawachi, 2000; Viswanath, 2006). Therefore, it is no surprise that people with higher education and household incomes have an increased odds of affording digital technology and accessing a larger social network which results in a greater likelihood of seeking news, researching product information, using the Internet for work, and seeking overall health information compared to those with less education and lower incomes (Hassani, 2006; Madden, 2003).

The third barrier preventing access to the potential benefits of ICTs involves the *lack of digital skills*. These skills traditionally align more with patient capacities than patient opportunities since it involves the instrumental skills of "operating digital equipment and skills of searching information using digital hardware and software" as well as strategic skills of "using information for one's own purpose and position" (p.

319). However, this access barrier also accounts for the lack of skills acquired due to the lack of opportunities for adequate education, sufficient skills training, real practice, or social support. Having opportunities to develop one's digital skills at work, school, or in certain hobbies can have an impact on the extent to which engagement occurs (van Dijk & Hacker, 2003).

The fourth access problem captures the *lack of significant usage opportunities* as contributing to existing information inequalities. Van Dijk (1997, 2005) predicted a "usage gap" between those who use digital technology for work and education compared to those who use it mostly for entertainment purposes. Those populations with the opportunities to use technologies for work and education will systematically advance and benefit from increasingly difficult applications of technology use while those who mostly use technology for entertainment purposes will continue with basic use and simple applications (Van Dijk, 1999). Furthermore, having "autonomous use" of technology or the freedom to use technology when and where one wants without the constraints of lines or library patronage is also an opportunity that may vary from person to person and have an overall effect on engagement behaviors (Hassani, 2006; Livingstone & Helsper, 2007).

### **Patient Engagement Motivations**

During times of uncertainty, patients can be stimulated to question their utility, helpfulness, and overall identities and may experience doubt and ambiguity about their selves, others, relationships, and features of a context (Brashers, 2001; O'Hair et al., 2003). In efforts to address or reduce this uncertainty, the motivation to do so is a function of (a) expectations about one's ability to execute the behavior ("efficacy expectations") and (b) expectations about the outcomes of engagement ("outcome

expectations”) (Bandura, 1977). Self-efficacy perceptions in particular play a critical role in influencing individual motivations and behavior-outcome links (Bandura, 1982). Self-efficacy does not reflect a person’s “true” but refers to an individual’s belief in his or her own capabilities to organize and execute the courses of action needed to exert effort, overcome obstacles, and achieve desired goals (Bandura, 1977; Eastin & LaRose, 2005). Efficacy expectations vary along three dimensions: magnitude, strength, and generality. *Magnitude* refers to one’s belief that he or she is capable of performing a graded series of tasks that range from low-magnitude expectations (low difficulty level) to high-magnitude expectations (high difficulty level). *Strength* refers to the certainty a person one has in his or her ability to perform a specific task. In other words, people can designate tasks they believe they can accomplish, and then provide a probabilistic judgment or “rate” the confidence they have in their ability to complete the task. Finally, the *generality* refers to the extent one’s efficacy expectations in one particular experience or task can extend to another situation. These three dimensions although not explicitly tested in this project are likely to influence the extent to which engagement behaviors are executed.

The important principle in Bandura’s theory is that self-motivated behavior such as engagement is based on the degree to which a person’s perceive a discrepancy between current state and desired state of things (e.g., current health status and desired health status). However, because people adopt and adhere to behavioral routines (or automatic behavior), it is difficult to activate or trigger people’s self-determination by artificial means (e.g., media messages). Instead, oftentimes a significant personal event or experience (particularly of the adverse or negative type) – what Skinner (1938) refers to

as a “stimulus” – is needed to activate or trigger people’s self-determination because it tends to alter their salient needs. Accordingly, the primary objective of this study is to conceptualize the role of internal and external triggers in stimulating patient engagement. In this context, I am particularly interested in conceptualizing the role that uncertainty plays in motivating individuals to engage available information platforms and social ties to satisfy dynamically evolving information and social support needs, as well as identifying the mechanisms and processes that predict the threshold of uncertainty beyond which people will be motivated to engage their information and social environment in this way. I argue that because some degree of health-related uncertainty or concern regarding one’s health status is ever-present, people can generally tolerate certain (normal) levels of uncertainty to be able to maintain existing habits and daily routines. Therefore, when the information cues (or signals) they receive from their environment regarding their health (e.g., campaign messages or physician advice) fall within tolerable levels, they have little or no motivation to seek further information or support needed to modify their existing habits or routines. Rather, people are more likely to actively and purposefully engage their environment when they experience a trigger event – an extreme, unexpected, and significant health event – either personally or vicariously (such as when a family member or a close friend experiences such event), because such event is capable of disrupting normal levels of uncertainty and crossing the threshold of illness uncertainty that can motivate active engagement with health communication. In other words, in this study degrees of uncertainty fall along a continuum. On this continuum, triggers represent a threshold where individuals are sufficiently motivated to actively engage with their information ecology.

### **Activation of Patient Engagement**

The notion of behavioral “triggers” already exists in the extant literature on behavior change, although it is represented by different concepts, including “determinants of behavior” (Strack & Deutsch, 2004) and “cues to action” (Rosenstock, Strecher, & Becker, 1988). One well-documented feature of triggers is that they cause a great deal of uncertainty or discomfort in individuals who are consequently motivated to reduce their uncertainty by actively seeking information from sources (interpersonal and mediated) that they can access in their environment (Brashers, Goldsmith, & Hsieh, 2006). Many frameworks have dedicated efforts towards explaining how uncertainty might be personally reduced or managed, including Berger and Calabrese’s (1975) uncertainty reduction theory, Sunnafrank’s (1986) predicted outcomes values theory, and Gudykunst’s (1993) anxiety/uncertainty management. However, these frameworks rarely seek to understand and explain uncertainty as a dynamic phenomenon and, consequently, have difficulty accounting for when and how much uncertainty must be present to motivate action. In this sense, a distinction between behavioral triggers and signals and how they influence human action may be useful.

#### **Signals and Triggers**

The human brain controls all human reactions and actions by receiving, screening, and processing different external stimuli through the sensory system. All sensory stimuli enter the brain in the form of signals that result from neurons firing in sequence along specific sensory pathways. To be able to process the enormous number of external stimuli that exist in the environment at any given moment, the human brain uses a system (the sensory register) for determining the importance of external stimuli to the individual. To

make this determination, the brain is using the individual's past experiences (which are stored in memory) as a benchmark. Research has shown that an incoming signal from the sensory system must be stronger than a certain threshold (which differs for each individual) to prompt or trigger action while signals that do not surpass this threshold are generally dismissed or ignored (Sousa, 2011).

The idea that individuals selectively attend to and process information received from their external environment is certainly not new. Classic persuasion theories such as social judgment theory (Sherif, 1936) and the elaboration likelihood model (Petty & Cacioppo, 1986) readily incorporate this principle into the explanation of how people react to information received from their environment, but seek to explain this process as a function of the relative importance of a stimulus to the individual (i.e., degree of ego involvement) as opposed to a function of some threshold that separates signals from triggers. This other type of explanation draws on the notion of inertia or habituation: familiar signals or cues in one's environment that were previously determined as not requiring immediate action will be largely ignored by force of habit unless they cross a certain threshold that signals the need in taking immediate action (i.e., perceived as a trigger). This threshold, which likely differs for each individual as a function of personal experiences and predispositions, defines the boundary between the "normal" and the "abnormal" in terms of interpreting external cues. As a rule, a cue judged to be "abnormal" is likely to garner more attention from the individual and is likely to motivate action if it is interpreted as urgent and significant to the person's well-being.

This, however, begs the question of how individuals recognize that the threshold that separates a normal, "no-action-required" signal from a trigger to action is reached.

As it turns out, this too is not a new question. A similar question has been raised, for example, in relation to the phenomenon of cognitive dissonance (Festinger, 1957) – i.e., how much dissonance a person must experience before he/she is motivated to take corrective action? The general answer given to this question is that action is a function of the degree or intensity of the discomfort a person's experiences. I propose that the same principle can be applied to answering the question about the threshold that separates signals from triggers. The difference is that the mechanism operating in this case is not a sense of discomfort (e.g., experienced guilt, regret, or doubts) but rather the degree of uncertainty regarding the external stimuli that a person is willing to tolerate. That is, I explicitly assume that uncertainty is not a dichotomous state (i.e., being uncertain or not) but rather that some degree of uncertainty about any aspect of personal or social reality is always present and dynamically changing as a function of internal and external changes experienced by individuals. In other words, we are all uncertain about some things all the time. To be able to function and execute our daily routines without being paralyzed by the omnipresence of uncertainty in our life, we must tolerate some degree of uncertainty, and the threshold of uncertainty we can accept without changing anything about our behavior is set individually based on our goals, predispositions, and past experiences. My task here therefore is to explain how people reassess their degree of tolerance of uncertainty following the presentation of signals (or cues) to determine if action is needed, which I do based on uncertainty management theories.

### **Uncertainty as a Trigger of Patient Engagement**

Uncertainty is well established as a triggering mechanism within models of information-management in which people will act to cope with the anxiety derived from



their uncertainties (see review in Afifi & Weiner, 2004). Uncertainty definitions and its management vary in the literature (Babrow, Kasch, & Ford, 1998). In general, uncertainty occurs “when details 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). Early theorists pointed to ways in which uncertainty was a negative, stress-inducing experience to reduce (Berger & Calabrese, 1975) or a type of “mental confusion” (Folkman et al., 1979, p. 276), while others highlighted the ways ambiguity can spark information-seeking and develop closeness and may be valuable to increase, maintain, or endure (Afifi & Weiner, 2004; Baxter & Wilmot, 1984; Berger & Bradac, 1982; Brashers, 2001). One of the earliest conceptualizations applied uncertainty specifically to the healthcare context and defined illness uncertainty as “the inability to determine the meaning of illness-related events” and as the “cognitive state created when the person cannot adequately structure or categorize an event because of the lack of sufficient cues” (Mishel, 1988, p. 225). Under this conceptualization, medical emergencies, diagnoses, and illness conditions ranging from the expected to unexpected act as uncertainty-laden stimuli events.

In general, theories of uncertainty management propose that during stimuli events, individuals undergo a cognitive appraisal process (i.e., interpretation, evaluation, and decision) of their degree of uncertainties to determine if there is enough of a discrepancy between their desired level of uncertainty and their actual level of uncertainty (Afifi & Weiner, 2002). If the discrepancy level is dismissible, they may avoid the stimuli and do nothing. However, if it has reached a critical point of salience, then they may be

sufficiently motivated to act and develop goals to reduce the uncertainty. To determine how to respond to stimuli events, patients will first undergo “primary appraisals” of the personal relevance of a stressor (which can be positive or negative), undergo a “secondary appraisal” of their resources and capacities for responding to the stressors, and then go through the “coping” process of executing the responses (Bandura, 1982; Lazarus & Folkman, 1984). To cope with the stress, people are simultaneously motivated to reduce their uncertainties and to find ways to positively frame things (Lazarus & Folkman, 1984). According to Ramirez et al. (2002), the strategies employed to address such goals are constrained or expanded by the different *types* of goals pursued (e.g., the pursuit of information or social support) and the *duration* of the goals (e.g., short-term goals may dictate more immediate and synchronous approaches than long-term goals). In this case, the strategies (such as engagement) are jointly dependent on the occurrence of stimulus events, the salience of the uncertainty discrepancy levels, and the resulting goals based on those levels.

We may therefore acknowledge that the need to manage the level of an uncertainty discrepancy can function to motivate engagement behaviors. Depending on how much the actual level of uncertainty deviates from a patient’s tolerable level of uncertainty, we can predict that this patient will (a) avoid, dismiss, or repress stimuli that are insufficient to induce enough uncertainty discrepancy (e.g., Brashers et al., 2002; Case et al., 2005; Pennebaker et al., 1990), (b) seek information that can reduce actual uncertainty so it drops to tolerable levels (Berger & Calabrese, 1975), or (c) increase the tolerable level of uncertainty they can manage or cope with. Essentially, patients move away from source-oriented models of communication and become more active actors in

their individual and collective health decision-making efforts by responding with communication behaviors such as engagement to aid in the construction, management, and resolution of the uncertainty (Babrow, Kasch, & Ford, 1998; Rimal et al., 1997). In this way, communication strategies are used to cope with illnesses and manage stress (Babrow & Mattson, 2003; Brashers et al., 2000; Brashers et al., 2004). Patients respond to their emotional and informational needs by engaging in communication actions of information or support seeking (Brashers, 2001), changing their evaluative orientations towards the uncertainty-inducing object, becoming more comfortable with accepting “conventionally sanctioned uncertainties” associated with illness (Babrow, 2001, p. 563), and reframing the uncertainty as a test of character, faith, or self-exploration (Babrow, 1992).

An important insight in the literature is that during times of “uncontrollable events” (Cutrona & Russell, 1990) such as the developments of an illness or medical condition (what I refer to as “stimuli events” throughout this work), people assess the gap between their desired levels of confidence and actual level of confidence before reaching a “sufficiency threshold” and responding to the specific losses involved (Chaiken, Giner-Sorolla, & Chen, 1996). In this study, uncertainty and its threshold are not explicitly measured, but prior work provides a strong basis for accepting a “tolerance for uncertainty” (Kellerman & Reynolds, 1990), the conscious management of “maximum” and “minimum” thresholds of uncertainty (Gudykunst, 1993; Gudykunst & Nishida, 2001), and uncertainty discrepancies as strong predictors of variance in information-seeking behaviors (Afifi & Weiner, 2004; Thompson, Bevan, & Sparks, 2012). Still, what

is missing from the current literature is a clear sense of how the tolerance threshold of uncertainty is formed and when it leads people to take actions.

Since the achievement of complete certainty is unlikely (Berger & Bradac, 1982), it seems reasonable to consider uncertainty as a pervasive and continued state that can vary in magnitude and intensity depending on circumstances (e.g., Brashers et al., 1998; Mishel, 1988). Previous studies generally support this conclusion, including Brashers et al. (1998) who described uncertainty as occurring throughout four phases of the HIV illness trajectory (at risk, diagnosis, latent, manifest) and Hilton (1993) whose participants reported uncertainty stemming from suspicious lumps in their breasts and lasting post-treatment in fear the cancer might return. And although illness uncertainty tends to decrease over time (Hughes, 1993; Liu et al., 2006) and sources of uncertainty change (e.g., concerns about the future to concerns about unanswered questions), patients still report uncertainty even five years post-treatment (e.g., Decker, Hass, & Bell, 2007). As such, the temporal dimension of uncertainty tends to range from short-lived (“Will I survive this surgery?”) to ongoing (spanning one’s life, career, and relationships) (Folkman, 1984; Mishel, 1988) and can potentially mean differing responses in terms of engagement.

In addition to the uncertainty tolerance threshold being a function of stage of disease, it is also important to recognize that individuals vary in how and to what extent they experience uncertainty when exposed to the same stimulus. People engage in subjective evaluations of the same stimulus based on their prior experiences and existing predispositions. Therefore, the degree of uncertainty discrepancy levels they experience and their personal degree of uncertainty tolerance vary dynamically across a continuum

ranging from signals (low uncertainty discrepancy, high tolerance of uncertainty discrepancy) to triggers (high uncertainty discrepancy, low tolerance of uncertainty). At one end of the continuum, *signals* are a type of stimuli associated with health-related information or cues characterized by a personally tolerable level of uncertainty. Signals can often take the form of lingering or expected health concerns largely contingent upon people's subjective judgments about its personal relevance, proximity or immediacy, concreteness, repetition, familiarity, novelty, and/or affective content of the signals they receive (Andrews & Shimp, 1990; Ferguson, 1999). Put differently, signals (e.g., health information received from health care providers or via other channels) can carry an accumulated weight or intensity (or lack thereof) of uncertainty depending on subjective factors. For example, a woman's family history of breast cancer signals risks associated with her personal health. Although she recognizes she has increased risk and could eventually be diagnosed with breast cancer, her level of uncertainty is still manageable and as a result dismisses the cue and chooses not to engage with her information ecology to reduce her uncertainty. There is a possibility that the uncertainty level associated with a signal or a collection of signals can remain below or approach the threshold of uncertainty. If the threshold is activated, the signal can evolve into a trigger.

At the other end of the continuum, *triggers* are also a type of stimuli but occur when a person reaches their maximum threshold of tolerable uncertainty and are activated to automatically or reflexively respond by reducing or managing the uncertainty. In other words, triggers produce more reactive or reflexive actions than signals. I propose in this study that once a person is triggered, his or her motivation to manage uncertainty causes his or her engagement behavior. For example, in the event a woman finds a lump in her

breast, her previously tolerable level of uncertainty may evolve into one that surpasses her threshold and she therefore becomes motivated to manage or reduce this level of uncertainty by engaging with her information ecology (e.g., seeking information online, speaking with a doctor, talking with a friend, etc.). Given the vast number of stimuli competing for people's attention, triggers are appraised as cues of importance (Hines, 2001) and surpass a certain threshold before activating behavior (Fiske & Taylor, 1991). Beyond stimulating information-seeking behaviors as immediate reaction to the unexpected event, and assuming that more than a single, immediate action is needed to dismiss this event and resume one's routine level of uncertainty, triggers are also sufficiently powerful to succeed where signals often fail, namely activating self-determination and engaging individuals in a process of self-regulation that is necessary for behavior change.

Stimuli, therefore, can originate as either signals or triggers. An unexpected diagnosis, for example, can immediately trigger engagement behaviors. Stimuli can also begin as signals and later evolve into triggers. The uncertainty associated with breathing difficulty, for instance, could be ignored at first, but as the symptoms persist and intensify over time, the signals accumulate and trigger engagement. There is also the possibility that triggers can eventually evolve back into signals after individuals have engaged with their information ecologies enough to ease their uncertainties. Following the logic of the agentic theory of human behavior (Bandura, 2001), we can expect that as triggered individuals have an opportunity to reflect on the information or support they acquired as a result of their engagement efforts, they reevaluate their personal needs and goals and can either continue to engage with their ecologies or readjust their uncertainty levels.

This framework differs from theories that categorize responses to uncertainty as passive, active, and interactive (e.g., Afifi & Weiner, 2004; Berger & Calabrese, 1975; Ramirez et al., 2002). I prefer instead to understand individuals' responses on a continuum of engagement, where latent engagement occupies one end of the continuum and manifested engagement occupies the more highly active end of the same continuum. Latent engagement is illustrated by the observation of Niederdeppe et al. (2007) that some people embed themselves in health information-rich environments by subscribing to sources with some health-related content such as certain magazines, television programs, and sections of newspapers (Johnson, 1997; Johnson et al., 2006). Although such patients (compared to those not embedded in this type of ecology) may differ in how exposed they are to health information, they are not completely passive in their information acquisition. A close look at additional examples of "passive" behaviors also suggest a latent level of engagement; for example, information acquired about a target through "unobtrusive observation" (Ramirez et al., 2002) and the reading of exchanged messages without participation (e.g., Barnes, 2001; Nonnecke & Preece, 2000; Teodoro & Naaman, 2013) are not entirely passive endeavors. In many cases, people may not even realize they are experiencing a trigger or uncertainty-inducing event and may react in a highly automatic and perhaps mindless fashion (Bargh & Chartrand, 1999).

On the other hand, manifested engagement occurs as patients consider alternative courses of action and what will enable them to take these actions; they actively and intentionally turn to others in their environment for information and support. Importantly, at this stage of the behavior change process they are motivated to engage information at much deeper levels than during their original information-seeking efforts that were

mostly directed at reducing the uncertainty caused by the trigger events. In particular, their information behaviors aim at achieving self-mastery (being knowledgeable and skilled about the change they seek), which is a crucial determinant of self-efficacy (Bandura, 1986). For example, one study found that after meeting with their health care providers (a stimulus event that potentially introduces or highlights areas of confusion or uncertainty for patients), many Internet users went online to search for information that either confirms or challenges the information provided by their physician as well as to search for additional information (Nicholas et al., 2003). Others retrieve information from the Internet prior to their medical consultation and bring with them that information to aid in their decision-making and communication with their healthcare providers (Anderson, Rainey, & Eysenbach, 2003; Berland et al., 2001; Broom, 2005). Additionally, strategic communication with others such as doctors, family, and friends can lead to more effective and efficient information seeking and optimal matching between individuals' needs and support received (e.g., instrumental, emotional, psychological, etc.) to adhere to their behavior change plan (Carver, Scheier, & Weintraub, 1989; Cegala, 2000; Thoits, 1995).

### **Patient Engagement Outcomes**

Based on the findings of previous research studies, I categorize the major outcomes of engagement as (1) proximal or immediate outcomes, (2) intermediate outcomes, and (3) distal or long-term outcomes. The anticipated *proximal* or *immediate* outcomes of engagement include increased knowledge (both declarative and procedural) regarding their health issue as well as regaining a sense of control over their health and obtaining the resources they need to this end. The *intermediate outcomes* of engagement



include patients' physical and mental coping with illness as well as the ability to respond effectively to challenges and setbacks. In the *distal* or *long-term outcomes*, engagement is expected to result in improved health status and quality of life outcomes for patients.

### **Short-Term Outcomes**

Patient engagement within information ecologies can have short to long-lasting impact on decisions about personal health care, treatment, and interactions. Evidence suggests that many outcomes – some beneficial and others detrimental – occur as a result of information-seeking, social support seeking, and sharing actions. One of the major proximal or immediate outcomes of engagement includes greater declarative knowledge about the health issue and procedural knowledge regarding the available treatment options. In the 2002 Pew study, for example, many searchers reported that learned information led to immediate outcomes (Fox & Raine, 2003): Information guided treatment decisions for an illness or condition (44%), led patients to ask doctors new questions or obtain a second opinion (38%), and led to changes in coping strategies and pain management (25%). However, learned information can also lead to negative outcomes such as “information overload,” when the rate, intensity, and meaning of the acquired information can cause stress, a widespread reduction in effective information management, and more hindrance rather than added value (see review in Hall & Walton, 2004). Additional information can also create greater awareness of conflicting medical information and confusion about right courses for treatment (Eysenbach, 2003).

Other short-term outcomes of engagement include an increase (but potentially also decrease) in perceived behavioral control, technological efficacy (i.e., perceived effectiveness and ease of use of technology), and self-efficacy to cope with the health

issue. Moreover, engagement can lead to the immediate attainment of sought-after social resources such as money, help at home, time flexibility at work, and reliable transportation to and from health care facilities, unless these are already available to the patient.

### **Intermediate Outcomes**

*Intermediate outcomes* of engagement include (a) the ability to cope physically and mentally with the health issue (to the extent it persists), (b) the ability to react quickly and effectively to potential setbacks or complications, and (c) adherence to treatment.

Intermediate outcomes from engagement include more developed and expert skills to handle health-related encounters. Users who engaged with ICTs, for example, have learned to employ more direct and interactive uncertainty-reduction strategies such as intermediate questioning and disclosing with their partners (Tidwell & Walther, 2002). More information-seeking actions can address the lack of knowledge associated with low levels of literacy and health prevention services (Andrus & Roth, 2002).

### **Long-Term Outcomes**

*Distal or long-term outcomes* of engagement include improved health and quality of life outcomes for that person (to the extent that the health issue remains under control) as well as predictions for future use of information ecologies. The fulfillment of social support needs, for example, has been associated with effective long-term success for health behavior change and sustained self-regulation (Wilfley et al., 2010; Wing & Jeffery, 1999). In fact, better health chances have been linked to informal social networks, involvement with social activities, and participation in organizations (Berkman & Breslaw, 1983; Rogers, 1996). Using self-rated health status as a good predictor of

mortality (see Idler & Benyamini, 1997 for review), frequent socialization with coworkers and attendance at religious services (two types of interpersonal engagement) were also found to have a strong positive correlation with health status, despite respondents' age group of young (ages 18-39), middle-aged (ages 39-65), and elderly (ages 65 and older) (Veenstra, 2000).

Engagement with one's information ecology can also imply long-lasting indicators of informational and social support. Information-seeking strategies can influence outcomes such as impression and relationship development (Ramirez et al., 2002). Those who engage with social networking sites such as Facebook tend to have more close ties, receive more support from their social ties, and have a greater trust for people than those who do not (Brenner, 2013; Hampton, Goulet, & Rainie, 2011).

Patients' successes with certain engagement strategies may impact and reinforce future decisions and strategies to engage with their information ecologies in the same or similar ways. According to Slater (1997), people tend to more readily process information aligned with their existing beliefs and may use this information to reinforce patterns of behaviors. Additionally, patients may develop and maintain newly learned patterns of in efforts to maintain subgroup norms. For example, research findings suggest that positive impressions and affinity formed over CMC can match that of face-to-face groups over time and lead to similarities in message content creation and style in online comments and sharing practices (Postmes, Spears, & Lea, 2000; Walther, 1993).

### **Putting It All Together: A Model of Patient Engagement**

The focal construct in this conceptual framework, patient engagement, is intended to represent a more active form of patient activism with regard to communication and

information than the account offered in the current health communication literature, one that encompasses a set of specific information and communication behaviors that individuals use to purposefully engage their information and social environments within the constraints (or affordances) of the ecological systems in which they are embedded. The model in Figure 1 describes the determinants and outcomes of patient engagement. Following the rationale summarized above, the model suggests that the motivation for patients to engage (i.e., actively seeking, sharing, or mobilizing information and other resources needed to cope with a health issue) becomes activated (as opposed to being caused) once a health-related stimulus event that one experiences personally or vicariously (e.g., a family member presenting acute illness symptoms) pushes a person to surpass their acceptable level of uncertainty. In other words, the hypothesized mechanism that links trigger events to a patient's engagement is *motivation* to manage a threshold of uncertainty about one's (or other's) health status. Consequently, once individuals are motivated to reduce their uncertainty, they can make sense of their situations by actively seeking information from sources that they can easily access (e.g., online sources, health care providers, family and friends) (Afifi & Weiner, 2004).

Once again, there is the possibility that some individuals ignore or suppress the uncertainty derived from the stimulus event and choose not to engage initially. Although they may be capable of engaging their environments and receive signals to engage, engagement will not occur unless they are sufficiently motivated to do so due by their uncertainty about their health status. This process of dismissing signals or avoiding the active pursuit of additional information allows people to maintain their current state of knowledge or beliefs (Brashers et al., 2000).

In addition to being motivated to engage, degree of engagement is also presumed to be a function of the person's ability to engage (that is, having the skills and competencies needed to perform the task of engaging systems or other people in one's environment) and the opportunity to engage. Recognizing that patient engagement is situated within the social and information ecology in which patients are embedded, it is assumed that the opportunity to engage is often beyond the control of the individual due to objective personal circumstances or environmental barriers. Thus, degree of engagement is expected to be high when motivation and ability to engage are high and patients are free to engage. However, the primary way in which patients engage their information and social environment (seeking, sharing, or mobilizing) is expected to vary (both between and for the same patient) as a function of patients' specific needs and abilities as well as a function of their illness status. For example, we can expect a patient who just received a cancer diagnosis to experience a high level of uncertainty that causes her to engage in intensive information-seeking behavior. Once this patient had an opportunity to learn more about her cancer and possible courses of treatment, she may more intensely engage in seeking resources and support from others that can help her with this process. As she receives treatment and experiences improvement in her cancer status, she may be more motivated and able to share what she learned with others, either for altruistic reasons or to boost her psychological well-being. She may also be motivated to mobilize others into action, thus engaging them in that way. The point of this example is to illustrate that patient engagement is dynamic as opposed to being fixed for the same patient over time, although it is difficult to represent and study its dynamic nature with cross-sectional data of the type used in this study.

The model in Figure 1 also outlines the expected outcomes of patient engagement. In general, we expect more engaged patients to demonstrate greater and more accurate illness-related knowledge (i.e., knowledge of causes, available treatment or prevention options, and the relative benefits and costs of each). We also expect them to possess a greater sense of efficacy and control regarding their health issue. The mechanism that accounts for this link is individual learning – as patients educate themselves about their health issue and treatment options, they are more knowledgeable and efficacious regarding their illness. Finally, if they were looking to obtain or secure resources other than information, we would predict that greater engagement would increase their likelihood of obtaining these (but these will greatly vary depending on personal needs and circumstances). These intermediate outcomes of engagement are generally expected to increase patients' ability to cope (physically and mentally) with their health status, unless patients experience adverse health events or encounter challenges that are beyond their control. In the long-run, and assuming that patients are able and self-determined to adhere to their treatment and wellness plan, we would expect them to experience favorable health and quality of life outcomes.

### **Research Question and Hypotheses**

The focus of this dissertation is on reconceptualizing patient engagement to reflect the more active role patients now occupy regarding decisions about their health due to their increased capacity and opportunities to engage with and secure relevant information and support in a networked society. The model of patient engagement I propose seeks to extend the conception of engagement from the state of being engaged (i.e., active information processing) to engagement as behavior (i.e., actions taken to seek, share, and

mobilize information and support from systems and others that a person can access in their social network). The most crucial assumption of this model is that patients themselves control their activation (as opposed to being activated by health care providers or health communication campaigns). That is, patients decide when to engage, with whom, and with what intensity or urgency to satisfy their information and support needs. According to the model, patients are continuously engaged with information and support in their environment as part of managing their health, but much of this engagement is rather dormant or latent. However, patients can switch to more active forms of engagement once they experience triggering stimuli – an event or abnormal change in their health status (or that of a loved one) that causes levels of uncertainty and concern that are greater than the threshold they can tolerate. When this happens, the model predicts that patients will exhibit elevated levels of engagement, but that the outcomes of engagement will also depend on their capability and opportunity to engage systems (information system, health care system, insurance system, etc.) and other individuals in their environment or ecology.

In general, testing this model empirically requires, ideally, the collection of longitudinal data on patients' experiences, degree of uncertainty, and engagement behavior (seeking, sharing, and mobilizing information and social support). However, such data were not available for the purpose of this study and secondary data sources had to be used instead. Therefore, the specific research question that guided the empirical study concerned the extent to which the primary hypothesized active ingredient of patient engagement (i.e., degree of discrepancy between uncertainty a patient's experienced following a triggering stimuli and that patient's tolerable degree of uncertainty) can

predict variations in patient engagement in reality, while reasonably controlling for factors that can determine patients' capability and opportunity to engage their social and information environment. The parts of the conceptual model actually tested in this study are in Figure 2.

The empirical test of the patient engagement model explicitly assumes that because health-related stimulus events vary in terms of severity and urgency, and therefore in the degree of uncertainty they cause in patients (Babrow, 2001; Brashers, 2001; Brashers et al., 2000; Mishel, 1988), we should expect to find differences in the information-seeking behavior of the individuals experiencing them. Based on the uncertainty management literature, I expected a linear, monotonic relationship between patients' information-seeking behaviors and the degree of uncertainty discrepancy associated with one's health status. The assumption is that patients who have recently experienced a health-related stimulus event associated with severe uncertainty discrepancies (trigger) will report greater information-seeking behaviors than patients who have recently experienced stimulus events associated with mild uncertainty discrepancies (signal) as well as individuals who have not experienced a health-related stimulus event at all (no trigger or signal). Because uncertainty discrepancy as a variable was not directly measured in this dataset, a proxy variable was created by combining information about a patient's chronic condition status (i.e., having or not having any chronic health problem or condition in the past 12 months) and this patient's exposure to a certain stimulus (trigger or signal) in the past 12 months. This combination produced six distinct groups of patients (see Table 2 for groupings based on stimulus types) that could be placed along different stages of the uncertainty discrepancy continuum, from



low to high uncertainty discrepancy (see Methods chapter for details on the characteristics of patients in each group): (1) Unconcerned Group had no pre-existing health conditions and experienced no health change or emergency, (2) Untroubled Group did have pre-existing health conditions but experienced no health change or emergency, (3) Noncommittal Group had no pre-existing health conditions but experienced a health change, (4) Cautious Group had pre-existing health conditions and experienced a health change, (5) Alarmed Group had no pre-existing health conditions and experienced an emergency, and (6) Concerned Group had pre-existing health conditions and experienced an emergency. In general, if the model is correct, we would expect to see that degree of patient engagement is sequentially greater for each patient group. Accordingly, the first hypothesis is as follows:

**H1:** Information-seeking behaviors will be highest for patients in the Alarmed and Concerned groups (the triggered groups) than for patients in other groups. In addition, patients who are signaled (Cautious) will be more engaged than patients who have not been signaled or triggered (Noncommittal, Untroubled, and Unconcerned).

Next, although patient engagement encompasses a range of communication and information behaviors (seeking, sharing, and mobilizing information and support), patients who are triggered are not assumed to pursue all engagement actions equally. Rather, depending on health status and uncertainty levels, patients may use one form of engagement more than they use others. Specifically, the initial uncertainty patients experience could be reasonably mitigated following an intensive information-seeking effort, and as they transition from diagnosis and initial treatment to illness management, patients may subsequently transition into less active forms of information-seeking and

may increase their support-seeking efforts instead so they may cope effectively with their illness. We can assume, for example, that people who are healthy and living without pre-existing health conditions, do not look for social support because they have no immediate need for it. Additionally, those who are considered triggered may not prioritize social support needs even though they exist. Perhaps they are still in information-seeking mode or experienced a single or temporary episode of severe uncertainty, sought information a few times and never felt the need to join a community of peer-patients.

Patients may also turn their attention away from seeking information and support to providing them to others in the same situation as they become more knowledgeable about their health condition and more skilled in managing it. Because triggered groups might seek information to ease their uncertainty discrepancies prior to sharing or contributing information, I expected that the group signaled and with pre-existing health conditions (Cautious Group) will be the group with the highest amount of sharing. Therefore, the second hypothesis is the following:

**H2:** In comparison to other groups, information-sharing behaviors will be highest for patients in the Noncommittal and Cautious groups because they experience mild uncertainty discrepancies (signals).

The final hypothesis predicts that support-seeking behaviors will be highest for patients with mild uncertainty discrepancies. Because patients may experience a mixed series of triggers and signals as a result of wavering levels of uncertainty, over time they may no longer need additional medical information about their condition. Moreover, they might not feel the need or readiness to share their experiences with others. However, they may turn to others for more coping-related information and support (Braithwaite et al.,

1999; Cline, 1999; White & Dorman, 2001). As such, those with pre-existing health conditions are more likely than those without pre-existing health conditions to actively seek out and join online communities of same-patients than patients who do not report having a chronic condition.

**H3:** Support-seeking behaviors will be highest for patients in the Cautious group, i.e., those who have a pre-existing health condition and have experienced a significant change in their health but no medical emergency.

## CHAPTER 4

### METHOD

This study uses data from the 2012 Tracking for Health Survey sponsored by the Pew Research Center's Internet & American Life Project (Princeton Survey Research Associates International, 2012). This survey is a reasonable (but by no means optimal) choice of a dataset for the purpose of testing the study's hypotheses because, in comparison to other publically available survey data, it includes a greater number of items related to health information-seeking, social support seeking, information-sharing, and health outcomes such as current health status and availability of social support (see Appendix A for survey items included in this study). Previous research using this particular dataset investigated the number of and the extent to which adults in the U.S. track a health indicator like weight, diet, exercise, or symptom (Fox & Duggan, 2013). However, given the cross-sectional nature of the data, it cannot be used to track the process of engagement as described in Figure 1. Rather, the data available can reasonably support comparisons of type and degree of patients' engagement with health-related information in their environment by their level of exposure to triggering and signaling events. Clearly, a major limitation of using the available data in this way is that the presence of the hypothesized mechanism that link triggers to engagement (i.e., degree of uncertainty discrepancy) cannot be confirmed directly. Instead, the data analytical approach taken here is designed to test key predictions of the proposed patient engagement model regarding differences in engagement by degree of exposure to trigger events with nationally-representative data on Americans' interactions with health information.

### **Sample Characteristics**

Interview responses are from a nationally representative sample of 3,014 adults (1,808 by landline and 1,206 by cell phone) living in the United States. African-American and Hispanic respondents were over-sampled to increase their likelihood of being adequately represented in the sample. Statistical weights were calculated to adjust estimates for differential likelihood of selection and non-response. The margin of sampling error is  $\pm 2.4$  percentage points (Princeton Survey Research Associates International, 2012). See Table 1 for full weighted and unweighted sample demographics. Weighted data were used in all analyses.

### **Data Collection Procedures**

Participants were contacted through a combination of landline and cell random digit dial (RDD) with up to seven attempts at contact. Interviews took place from August 7 to September 6, 2012 and were conducted in English and Spanish by the Princeton Survey Research Associates International. All phone numbers had equal probabilities of being drawn within each strata. Among landline interactions, interviewers requested to speak with the youngest male or female currently home, and if not available, the youngest adult of the opposite sex. This systematic approach meant to mirror the population in terms of age and gender was combined with a cellular phone sample. Among the cellular phone interviews, interviewers attempted to ask questions of the person who answered the phone given they were an adult and in a safe place to answer questions. To compensate for sampling bias that may have resulted from nonresponse, a multi-staged weighting process was used in the original survey analysis of this data from Pew and will be used in all analyses. Specifically, the first stage divided the proportion of the

population from each stratum by the proportion of sample drawn from the stratum and the second stage corrected for different probabilities of selection based on the number of adults in each household and each respondents telephone use (i.e., whether the respondent has access to a landline, to a cell phone or to both types of phone) (Princeton Survey Research Associates International, 2012, p. 25-26).

## **Measures**

### **Dependent Variable: Engagement**

The dependent variable of engagement in this study is measured through the combination of three types of actions: information seeking, support seeking, and information sharing. Aligned with previous work (Junco, 2012), each action under engagement was operationalized in terms of frequency of participation (e.g., how often person is involved in certain activities). Although mobilizing is considered another major form of engagement as explained in the conceptual framework, items explicitly capturing efforts to mobilize others into collective action are unavailable in this dataset.

**Information-Seeking.** Information-seeking behavior is a primary dependent variable related to engagement. As discussed in the first two chapters, health-related stimuli can elicit varying degrees of uncertainty. To better cope with or manage resulting uncertainty discrepancies, people often engage in communication behaviors such as the seeking of health information from mediated sources (e.g., Internet) or interpersonal sources (e.g., close family members, friends) (Afifi & Weiner, 2004; Babrow et al., 1998). Since a person will more likely engage with a greater number of CMC strategies or resources as the salience of the information-seeking goal increases (Ramirez et al., 2002), a composite count variable was created that represents this dimension.

The composite variable for information-seeking behaviors included items that specifically looked at behaviors done in the last 12 months. One multiple response question asked respondents whether they have looked for information online about certain health or medical issues, either for themselves or someone else in the last 12 months about (1) a specific disease or medical problem, (2) a certain medical treatment or procedure, or (3) medical test results. Also included in this variable were items that asked respondents whether in the last 12 months, they (4) ever went online specifically to try to figure out what medical condition they or someone else had, (5) signed up to receive email updates or alerts about health or medical issues, (6) read or watched someone else's commentary or personal experience about health or medical issues online, (7) posted a specific health question, comment, or story online about their own personal health experience, (8) consulted rankings or reviews of doctors or other providers, (9) consulted online rankings or reviews of hospitals or other medical facilities, and (10) consulted online reviews of particular drugs or medical treatments. Possible responses were "Yes," "No," "Don't Know," or "Refused." Participants were assigned an information seeking score based on the sums of their affirmative responses to these survey questions. These scores ranged from 0 (low information seeking) to 10 (high information seeking) with  $M = 2.04$  and  $SD = 2.30$ . The distribution of this variable was approximately normal, so no transformation was necessary.

**Support seeking.** To capture support-seeking actions, a discrete variable was used that asked respondents about any pursuits or interests in joining a patient community: In the last 12 months, have you gone online to find others who might have

health concerns similar to yours. About 13.3% of respondents reported seeking other patients.

**Information sharing.** Three items from the Tracking for Health survey combined to form a composite count variable that captures patients' acts of sharing health information or experiences. Items included in the sharing variable asked participants to reflect on other information they have shared online: "Thinking again about health-related activities you may or may not do online, have you (1) posted a review online of a doctor, (2) posted a review online of a hospital, or (3) posted your experiences with a particular drug or medical treatment online." Possible responses were "Yes," "No," "Don't Know," or "Refused" (see Appendix A, Question 11). Because the distribution of this variable was very skewed (92% of respondents responded "No" to having shared health-related activities online), it was recoded into its binary version ( $M = 0.09$ ,  $SD = 0.29$ ) to retain intuitive meaning.

### **Independent Variables: Uncertainty Discrepancy**

The primary independent variable in this study is the degree of uncertainty discrepancy experienced by a patient. Because this variable was not directly measured in the dataset, a composite variable was created from combining information about a patient's chronic condition status (i.e., having or not having any chronic health problem or condition in the past 12 months) and this patient's exposure to a certain stimulus (trigger or signal) in the past 12 months. A signal-type stimulus was captured using responses to one survey item ("In the last 12 months, have you personally experienced any significant change in your physical health?"). About 16% of respondents reported a noticeable change in their health. To represent triggering stimuli events, responses to two



survey questions were used: (a) in the last 12 months, have you personally faced a serious medical emergency or crisis; and (b) in the last 12 months, have you personally gone to the emergency room or been hospitalized unexpectedly. Responses to these two items were associated (Chi-square = 3134,  $df = 1$ ,  $p < .001$ ) such that 70% of respondents facing a serious medical emergency in the past year also reported a trip to the emergency room. However because a non-trivial percentage of respondents experienced one but not the other, if respondents answered “Yes” to any or a combination of these questions, they were placed into the *Triggered Group (TG)*. Overall, about 20% of the respondents ( $n = 602$ ) reported having experienced some type of serious medical emergency/crisis or hospitalization.

Based on participants’ chronic condition status and responses to triggering or signaling stimuli, six distinct groups of respondents were created to produce a probable continuum of uncertainty discrepancy (see Table 2): (1) Unconcerned Group, (2) Untroubled Group, (3) Noncommittal Group, (4) Cautious Group, (5) Alarmed Group, and (6) Concerned Group.

**Unconcerned group.** As a control group, individuals who neither experienced a recent emergency nor are currently experiencing pre-existing medical conditions were placed into the *Unconcerned Group (UNC)*. Roughly 43% ( $n = 1307$ ) of the sample reported not having experienced any trigger or signaling stimulus in the last 12 months. These patients, as reflected in H3, are predicted to report the least amount of engagement behaviors compared to all the other groups.

**Untroubled group.** People with a pre-existing health condition that experienced no significant change in their health or any medical emergency (no trigger, no signal)

were placed into the *Untroubled Group* (UNTR). Slightly more than a quarter (29% of all respondents or  $n = 792$ ) were included in this group. Like the Unconcerned Group, these patients are also predicted to report low engagement behaviors. However, as per H1, the Untroubled Group is predicted to report more information-seeking behaviors than the Unconcerned Group.

**Noncommittal group.** People without a pre-existing health condition that experienced a significant change in their physical health but no extreme event (signaled) were placed into the *Noncommittal Group* (NON). In line with H2, these patients (5.5% of all respondents or  $n = 151$ ) are expected to report a higher level of support-seeking behaviors compared to the other groups.

**Cautious group.** People with a pre-existing health condition that experienced significant change in their health but no medical emergency (signal) were placed into the *Cautious Group* (CAU). As reflected by H2, these patients (5.7% of all respondents or  $n = 156$ ) are expected to report high support-seeking behaviors since no imminent emergency exists but they may need to cope with the persistent uncertainty associated with their condition.

**Alarmed group.** People without a pre-existing health condition that experienced an unexpected adverse health event (trigger) were placed into the *Alarmed Group* (ALR). Aligned with H1, this group of respondents (about 8% of all respondents or  $n = 225$ ) are expected to report the greatest degree of information seeking relative to all other groups because of the pressing and highly uncertainty-inducing nature of an unexpected health event.

**Concerned group.** People with a pre-existing health condition that experienced no significant change in their health but did experience a medical emergency (trigger) (4.7% of all respondents or  $n = 129$ ) were placed into the *Concerned Group*. Aligned with H1, these patients are also expected to report high levels of information-seeking similar to that of the Alarmed Group.

### **Control Variables**

Several control variables were used in the analyses across the six patient groups including sex, education, race, income, health insurance coverage, marital status, internet use, and parental or guardianship status. These were chosen because they potentially determine patients' capacities and opportunities to engage with their information ecologies. Because the relationship between the IV (patient group membership) and the DVs of engagement are likely confounded with the effect of external variables, it is important to control for these in the analyses to minimize bias in estimates of the relationship.

### **Data Analysis**

The first part of the analysis examined the frequency distribution of the IVs and DVs. Descriptive statistics were generated for all variables (see Table 1). The second part of the analysis involved the cross-tabulation of the IVs and DVs with the covariates. A bivariate correlation matrix was derived given that the variables are binary or interval (see Table 3). The goals of this part of the analysis were to (1) identify which covariates (e.g., race, education, etc.) are strongly correlated with the DVs (information seeking, information sharing, and support seeking) and (2) identify which covariates are strongly correlated with one another so that they could be excluded in the multivariate model to

avoid multicollinearity bias. The third and final part of the analysis predicted the DVs from the IVs while controlling for covariates and using the appropriate multivariate procedure in each, depending on the nature of the DV (continuous or categorical).

## CHAPTER 5

### RESULTS

#### Hypothesis One

A one-way ANCOVA was conducted to test the first hypothesis that information-seeking behaviors will be highest for patients in the Alarmed and Concerned groups, who have severe uncertainty discrepancies (triggers), in comparison to those who have recently experienced stimuli with mild uncertainty discrepancies (signal) as well as individuals who have not experienced a health-related stimulus event at all. The variables included in the model as covariates were age, sex, education level, income, health insurance coverage, Internet use, and parental/guardianship status.

According to the chart in Figure 3, the relationship between information-seeking behaviors and patient group membership is fully linear, therefore lends only partial support to H1 (although this pattern may be an artifact of the relatively small size of the Cautious group). The predicted main effects of patient group was significant:  $F(1, 5) = 5.28, p = .000$ , suggesting that at least one of the six patient groups is different than the others. The partial eta square (see Table 4) for the effect of patient group suggests that this variable accounts for 12% or half of the total variance explained by all the variables in the model ( $R\text{-square} = 0.24$ ). This variable also has a strong correlation with information seeking and is not strongly correlated with other covariates (see Table 3).

Overall, although, as expected, information seeking was highest for the Alarmed Group, the Cautious Group demonstrated more information seeking than the Concerned Group. According to the confounder-adjusted means for each patient group, information seeking was highest among the Alarmed Group ( $M = 2.59, SE = .17$ ), next the Cautious

Group ( $M = 2.47$ ,  $SE = .20$ ), the Concerned Group ( $M = 2.26$ ,  $SE = .223$ ), the Noncommittal Group ( $M = 2.12$ ,  $SE = .20$ ), the Untroubled Group ( $M = 2.11$ ,  $SE = .10$ ), and the lowest among the Unconcerned Group ( $M = 1.78$ ,  $SE = .09$ ).

### **Hypothesis Two**

For estimating the effect degree of uncertainty discrepancy on information-sharing as engagement, a binary version of information-sharing (shared vs. not shared) was used given that about 90% of respondents did not report sharing information, making the continuous version of this variable highly skewed. As a result, a multiple logistic regression was used to estimate the relationship, controlling for covariates.

The results of this analysis (see Table 5) show a statistically significant effect of uncertainty discrepancy, although not a very large one. The odds ratio (OR) value associated with patient groups is 1.14 and suggests that as patients fall further along the continuum toward higher levels of uncertainty discrepancy, the odds of information-sharing behaviors increases by 14%. Additionally, the chi-square test of independence found that the relationship between information-sharing behaviors and patient groups was significant,  $\chi^2(5, N = 214) = 12.50$ ,  $p < 0.03$ . The Cautious and Concerned groups were more likely to share information than patients in the other groups. Notably, the number of cases within each patient group who reported information sharing is small and thus makes it difficult to offer an informed comparison of the percentage of members in each group who shared information. However, the percent of those who share is higher for higher levels of uncertainty.

Overall, partial support was found for H2. Information sharing behavior was found highest for the Cautious group, but not for the Noncommittal group as expected,

despite both groups classified as reporting mild uncertainty discrepancies (signals). Instead, the Concerned group emerged as a group more likely to share information.

### **Hypothesis Three**

Similar to H2, results from the logistic regression analysis about support-seeking behaviors show that patient groups have a statistically significant effect but not a very large one (Table 6). The OR value associated with patient groups is 1.19 and suggests that as patients fall further along the continuum of uncertainty discrepancy, the odds of support-seeking increase by 19%. Additionally, the chi-square test of independence found that the relationship between support-seeking behaviors and patient groups was significant,  $\chi^2 (5, N = 295) = 29.10, p < 0.001$ . Interestingly, the Cautious and Alarmed groups again were more likely to seek support than other groups. Thus, H3 was generally supported. Support-seeking behaviors were highest for patients in the Cautious Group, those patients who have a pre-existing health condition and have experienced a significant change in their health but no medical emergency.

## CHAPTER 6

### DISCUSSION

The major goals of the current research were to conceptualize, examine, and test differing pathways to patient engagement. Accordingly, a conceptual patient engagement model was created based on a review of existing work. An important goal of the empirical test utilized in this study was to confirm the underlying rationale of the model according to which the likelihood of patient engagement increases with the size of the uncertainty discrepancy a person experiences following a stimulus (trigger or signal). Specifically, I distinguished among six groups of patients based on the combination of three variables: (1) whether or not they have a pre-existing medical condition, (2) whether or not they have experienced a triggering stimulus event (unexpected medical or health emergency in the past 12 months), and (3) whether or not they experienced a signaling stimulus event (significant change in their physical condition) in the past 12 months and compare the degree and scope of their health information-seeking behavior.

The analysis found statistically significant evidence that suggests patient group membership (a proxy measure of uncertainty discrepancy size) is indeed associated with patient engagement behaviors. Overall, signaled patients did not demonstrate *less* engagement than triggered patients. Instead, they demonstrated *different types of engagement* depending on the strength of their uncertainty discrepancies. Partial support was found for H1 and H2, and full support for H3. Findings suggest that there may be an inverted U-shape rather than a positive linear relationship that may be a better approximation of the relationships between patients' level of uncertainty and the DVs of



information seeking, information sharing, and support seeking between uncertainty discrepancies and patient engagement.

### **Information Seeking Highest for the Alarmed Group**

Partial support was found for H1; information-seeking behavior was found highest amongst the Alarmed and Cautious Groups, but not the Alarmed and Concerned groups as hypothesized. The original assumption was that patients who have been triggered by a recent medical emergency (Alarmed and Concerned groups) would report the highest information seeking. However, findings from this analysis found that the group with a pre-existing medical condition plus a signal (Cautious Group) and the group without a pre-existing medical condition plus a trigger (Alarmed Group) had the highest information-seeking behaviors. This finding suggests that patients are at a heightened state of engagement with their information ecologies not only during unexpected events associated with high uncertainty, but also during times when mild uncertainty occurs in combination with a pre-existing medical condition. See Table 7 for a summary of findings.

A possible explanation for why the Cautious group emerged as high in information-seeking behaviors is because the combination of a pre-existing medical condition combined with significant health change was significant enough to surpass the threshold of uncertainty. Additionally, the Alarmed group may seek more information due to their lack of experience with a pre-existing medical condition or a lack of understanding of triggering stimuli.

One potential explanation for why the Concerned Group reported less information seeking than the Cautious and Alarmed groups is because their experiences with a pre-

existing medical condition may make them more prepared to experiencing a medical emergency. It is also possible that their medical emergency occurred around the same time as learning about their pre-existing medical condition. At this point, the initial shock of these experiences may position them in less of an information-seeking phase and in more of an information-consumption phase in which others (e.g., physicians, family members) push information towards them.

Those in the Unconcerned Group, as expected, had the lowest information-seeking behaviors. This follows logically given that these respondents have no cause for concern or immediate need to reduce their uncertainties. As hypothesized, those in the Untroubled and Noncommittal Groups reported more information seeking than the Unconcerned Group and less information seeking than the Cautious, Alarmed, and Concerned Groups. This aligns with the expectations that patients need to reach an activation threshold prior to seeking out information. A pre-existing medical condition or a significant health condition in and of itself are not enough to activate that threshold.

#### **Information Sharing Highest for the Cautious Group**

Second, partial support was found for H2; information-sharing behaviors was, in fact, highest for patients in the Cautious Group, but the Concerned group reported more information sharing than the Noncommittal Group. As predicted, the Cautious Group emerged as the cohort most likely to share information. This makes sense given that these patients have accumulated knowledge associated with their pre-existing medical conditions and are not as preoccupied as the other groups immediately addressing a trigger. These corresponding attributes and insights associated with the Cautious Group support Van den Hooff and de Ridder's (2004) findings that members will sometimes

disseminate one's acquired knowledge to outside members the more he or she has collected information.

Interestingly, the Concerned Group emerged as reporting more information-sharing behaviors than the Noncommittal Group. The original premise was that the Noncommittal Group with its mild uncertainty discrepancies would be better positioned than the triggered groups to share information since they were neither dealing with a pre-existing medical condition nor with an emergency stimuli. However, there is a possibility that the uncertainty associated with a significant health change among those in the Noncommittal Group is not enough to motivate information sharing. It is reasonable to rationalize that a prior (acute) awareness to the susceptibility of a health condition plus the actual activation and manifestation of the concerns yields more information sharing than if knowledge of the stimuli was purely novel. The Noncommittal Group also may not be experienced enough in their health change to feel comfortable to post a review online of a doctor, hospital, drug, or medical treatment.

On the other hand, the Concerned Group with their experiences with pre-existing medical conditions in combination with a medical emergency may be activated enough to share lessons with others and contribute to the collective knowledgebase. They may know enough about what information already exists and what would be valuable to know for others in similar positions. Additionally, patients who experience a trigger and have a pre-existing medical condition may share for the purpose of validation or catharsis (Sanford, 2010). This also supports illness uncertainty findings from Checton et al. (2012) who found that sharing allows people to cope with the complexity and unpredictability of health conditions.

As expected, the Unconcerned and Untroubled Groups reported the least amounts of information sharing. This is not surprising since they lack signals or triggers to remind them or make the uncertainty experience salient enough to act. Also not surprising is that the Alarmed Group did not report high information-sharing behaviors. Similar to the Noncommittal Group, those alarmed patients are likely seeking information about their medical emergency or are not yet at the point to which they are comfortable sharing information about their experiences.

### **Support Seeking Highest for the Cautious Group**

Finally, supporting evidence was found for the third hypothesis where support-seeking behaviors were reported highest among patients in the Cautious Group. Compared to the other groups, these patients reported a pre-existing medical condition and experienced a mild uncertainty discrepancy. Based on the patient engagement model, these patients seek less medical information when experiencing signaling stimuli because there can lack an immediate need or necessity to learn more about their conditions. Instead, these patients may need more social support to better cope with rather than learn more about their conditions. According to Burleson (2009b), the process of social support seeking can aid in the cognitive processing of the person's experience. This aligns with the premises of those in the Cautious Group; they may not need to immediately address a medical emergency, but may still harbor uncertainties towards their conditions that can induce feelings of stress, discomfort, and anxiety (Cohen, Gooleib, & Underwood, 2000; Gurin et al., 1960; Rosenblatt & Mayer, 1972).

The Alarmed Group was second behind the Cautious Group in terms of high support seeking. This is not surprising given that patients who recently experienced a

medical emergency are likely needing the support of others to cope with the uncertainty of their health experience. Recall that the Alarmed Group also reported the most information-seeking behaviors. Their lack of experiences with a pre-existing medical condition and with a medical emergency put them at a unique position to need informational as well as social support. Unsurprisingly, the Unconcerned and Untroubled Groups reported the lowest social support-seeking behaviors behind the Noncommittal and Concerned Groups. This supports the overall premise that the lack of signals or triggers is tied to less patient engagement.

In summary, differing levels of engagement were observed as a function of uncertainty-based stimuli and provide support for the conceptual patient engagement model discussed throughout this work. The study's results may illustrate the need for a more responsive health care system considerate of individual patients' motivations, opportunities, and capabilities. Consistent with the model's prediction, signaled patients like those in the Cautious Group do seem to engage with their information ecologies for the purposes of seeking social support rather than informational support which emerged as a higher behavior among triggered patients in the Alarmed Group. This supports the idea that patients do not necessarily need to *reduce* their uncertainty discrepancies but rather find ways to *cope* with their uncertainty discrepancies. The findings suggest that triggered patients seek care in many forms, not just in information, to address their uncertainty discrepancies.

Subsequent studies on patient engagement should consider a more longitudinal design in which the same individuals' engagement behaviors are observed over an extended period of time. This could provide more insights on the short-term and long-

term effects of more contextual factors that may affect health and overall trends in engagement such as inequality, poverty, and educational disadvantages. Future work should also aim to test the entirety of the model inclusive of mobilization items and more robust measures of uncertainty discrepancy size (versus a proxy). Findings could have practical implication for health communication; for example, signaling a shift to focus less on changing people's motivations to engage but more about building their capacity and opportunities to engage.

### **Limitations**

Some important limitations of this study must be noted. First, as noted above, given the limitations of the dataset used in terms of the variables included, the hypothesized mechanisms underlying patient engagement cannot be tested directly and the findings of this study cannot empirically confirm their presence. Another limitation is the incompleteness of the included measures (e.g., uncertainty was measured via proxy items, mobilization was out of the scope of this study). In addition, the cross-sectional nature of the data and the crude measurement of key variables time-wise (most questions ask about something that happened in the past year) preclude the ability to establish temporal order among the variables in the analysis (although it is clearly more logical to assume that engagement is motivated by a trigger event as opposed to the trigger event being a potential outcome of engagement). Moreover, perhaps a more time-sensitive, well-targeted survey and/or technology-enabled tracking and sensing study aimed at control and experimental groups (e.g., patients going through routine check-ups versus patients just diagnosed) could better capture the constructs of interest especially as they relate to immediate or gradually developing engagement behaviors.

Lastly, while several variables included in the dataset can be used to assess the effect of differential access to information on engagement, variables that directly measure individuals' competencies (or even perceived competencies) to engage information via ICTs or personal contacts are not included. Consequently, the current study would not be able to fully assess the contribution of a person's ability and opportunity to engage information to individual variations in engagement within the sample. On the other hand, because a nationally-representative sample of American adults are represented in the dataset, it would be possible to determine the extent to which experiencing a trigger event is associated with observed variations in patient engagement.

## **CHAPTER 7**

### **CONCLUSION**

This study sought primarily to make theoretical and conceptual contributions to health communication scholarship by providing an explication of engagement grounded in fundamental communication behaviors for responding to engagement. This study advanced a specific explication of patient engagement, a variable previously underdeveloped in the existing literature. The project explored the plausibility of the patient engagement model by testing some of its key predictions with nationally representative data and positioning individuals as agentic social actors motivated by uncertainty discrepancies. Additionally, this study provided a more dynamic conceptualization of patient engagement within an information ecology framework that involves factors of motivation, opportunities, and capabilities, which is necessary to advance both research and practice beyond the current emphasis on transfer and dissemination of health information. This investigation helps us understand how different types of stimuli varying in uncertainty discrepancy strength may affect the ways and extent people exert engagement actions of seeking information, seeking support, and sharing health-related information.

#### **Contributions of this Study**

This dissertation sought to fill a gap in health communication scholarship by providing several theoretical and conceptual contributions. The first major contribution of this study is the conceptual patient engagement model which uniquely recognizes and positions patients' communication and information behaviors (engagement) on a



multifaceted, dynamic continuum within an information ecology framework influenced by factors such as motivation, capability, and opportunity.

The second major contribution of this study is the specific explication of patient engagement, a variable previously underdeveloped in the existing literature. The explication of patient engagement in the model acknowledges the dynamic and pervasive natures of both uncertainty and engagement within the behavior change process. It includes descriptions of the major antecedents and potential outcomes to engagement, in terms of patients' abilities to mobilize and secure the information and other resources they need to cope effectively with their health issues. For uncertainty, the amount of uncertainty is not what causes engagement but the discrepancy between the desired and actual levels, which ranges from mild to severe, and can vary over time. For engagement, this model assumes patients are always somewhat engaged to the cues happening around them but that the status of uncertainty discrepancies can substantiate latent engagement or manifest engagement actions such as information seeking, social support seeking, sharing, and mobilizing.

Thirdly, this study found evidence for the ways engagement types vary depending on the strength of one's uncertainty discrepancy. The findings can inform the ways health communication scholars frame support resources and target patient groups with and without pre-existing medical conditions. A fourth contribution of the study includes improving the overall understanding for how different types of triggered or signaled uncertainty discrepancies may affect the ways and extent to which people seek information, seek social support, and share health-related information. This more nuanced understanding of patient engagement is impactful for advancing both research

and practice beyond the current emphasis on transfer and dissemination of health information. In summary, this study outlined a preliminary empirical test of the key assumptions of a patient engagement model based on recently collected cross-sectional data about the health information and communication behaviors of a nationally representative sample of U.S. adults. This empirical model tests a portion of the conceptual model but provides preliminary evidence critical for laying foundational components of the patient engagement model in future studies.

Table 1

*Sample Demographics N = 3,104 (Adopted from 2012 Tracking for Health Survey Report)*

	Parameter	Unweighted	Weighted
Gender	%	%	%
Male	48.6	44.4	48.9
Female	51.4	55.6	51.1
Age			
18-24	12.8	10.0	12.18
25-34	18	12.4	17.5
35-44	17.2	13.2	17.3
45-54	19.0	17.8	19.2
55-64	16.0	18.5	16.0
65+	17.0	28.1	17.3
Education (changed)			
Less than HS Graduate	13.3	9.0	11.7
HS Graduate	30.4	27.7	30.6
Some College/Assoc Degree	28.5	26.0	28.8
College Graduate	27.8	37.3	28.9
Race/Ethnicity			
White/not Hispanic	67.8	63.0	68.1
Black/not Hispanic	11.5	16.8	11.8
Hispanic – US born	6.6	7.6	6.6
Hispanic – born outside	7.4	6.8	7.0
Other/not Hispanic	6.7	5.7	6.5
Region			
Northeast	18.3	16.4	19.2
Midwest	21.7	19.0	22.1
South	26.8	41.5	36.1
West	23.2	23.0	22.6
County Population Density			
1 – Lowest	20.1	18.8	20.4
2	20.0	18.0	20.1
3	20.1	18.9	20.2
4	20.2	20.0	19.9
5 – Highest	19.6	24.4	19.3
Household Phone Use			
Landline Only	7.0	7.9	7.2
Dual – few, some cell phone	39.0	54.4	40.3

Dual – most cell phone	18.8	16.9	18.9
CPO	35.2	20.8	33.6

Table 2

*Patient Groupings based on Stimulus Types*

	CONTROL No Health Change or Emergency	SIGNALED Experienced Health Change	TRIGGERED Experienced Emergency
Without Pre- Existing Health Condition	Unconcerned Group <i>n</i> = 1307, 43%	Noncommittal Group <i>n</i> = 151, 5.5%	Alarmed Group <i>n</i> = 225, 8.2%
With Pre- Existing Health Condition	Untroubled Group <i>n</i> = 792, 28.7%	Cautious Group <i>n</i> = 156, 5.7%	Concerned Group <i>n</i> = 129, 4.7%

Table 3

*Covariate Percentages within Each Patient Group*

Covariates	X <sup>2</sup>	Patient Group					
		Unconcerned	Untroubled	Noncom- mital	Cautious	Alarmed	Concerned
Sex							
Female	.000***	n=1307 (47.4%)	n=792 (28.7%)	n=151 (5.5%)	n=156 (5.7%)	n=225 (8.2%)	n=129 (4.7%)
		604 (49.5%)	533 (58.2%)	92 (66.7%)	71 (57.7%)	175 (63.6%)	52 (47.7%)
Race							
White	.000***	838 (70.2%)	684 (76.3%)	82 (60.3%)	71 (60.2%)	198 (73.6%)	70 (64.8%)
Black	.006*	198 (16.6%)	152 (16.9%)	39 (28.7%)	27 (22.9%)	57 (21.2%)	20 (18.5%)
Asian	.004*	48 (4%)	18 (2%)	2 (1.5%)	6 (5.1%)	2 (.7%)	6 (5.6%)
Hispanic /Latino	.000***	207 (17.1%)	79 (8.7%)	25 (18.2%)	29 (24.2%)	30 (11%)	22 (20.2%)
Education							
Less than High School	.000***	82 (6.8%)	77 (8.5%)	20 (14.5%)	14 (11.4%)	38 (14.1%)	5 (4.6%)
High School Degree	.293	323 (26.6%)	270 (29.7%)	44 (31.9%)	27 (22%)	74 (27.4%)	33 (30.6%)
Less than College	.393	293 (24.1%)	233 (25.6%)	43 (31.2%)	37 (30.1%)	70 (25.9%)	30 (27.8%)
College Degree	.002**	302	167	20	24	53	25

Postgraduate Education	.028*	(24.9%) 214 (17.6%)	(18.4%) 162 (17.8%)	(14.5%) 11 (8%)	(19.5%) 21 (17.1%)	(19.6%) 35 (13%)	(23.1%) 15 (13.9%)
<b>Income</b>							
Above Median Income	.000***	513 (52%)	309 (41.8%)	26 (23.4%)	48 (42.5%)	61 (28.8%)	41 (45.6%)
Insurance							
Has Health Insurance	.000***	980 (80.3%)	834 (91%)	116 (84.1%)	90 (73.2%)	251 (91.3%)	89 (81.7%)
Marital Status Lives with Partner (Not-Single)	.015*	686 (56.4%)	518 (57.2%)	65 (47.4%)	67 (54.9%)	128 (46.9%)	55 (50.5%)
<b>Internet Use</b>							
At Least Occasional Internet Use	.000***	1022 (83.7%)	639 (69.8%)	103 (74.6%)	111 (90.2%)	167 (60.7%)	98 (89.9%)
At Least Occasional Internet Use on Cell Phone, Tablet or Mobile Handheld	.000***	740 (60.7%)	353 (38.7%)	62 (44.9%)	87 (71.3%)	90 (32.8%)	74 (67.9%)

Parental/Guardian ship Status							
Parent/Guardian of any Children Under Age 18	.000***	389 (31.9%)	153 (16.7%)	43 (31.2%)	57 (46.7%)	34 (12.4%)	39 (35.8%)

\* =  $p < .05$ , \*\* =  $p < .01$ , \*\*\* =  $p < .001$ . Numbers in parentheses indicate column percentages.

*Note.*



Table 4

*Analysis of Covariance (ANCOVA) of Information Seeking*

Parameter	B	Std. Error	t	Sig.	95% Confidence Interval		Partial Eta Squared
					Lower Bound	Upper Bound	
Intercept	.299	.294	1.017	.309	-.277	.875	.000
Internet Use	1.751	.125	13.984	.000	1.506	1.997	.082
Age	-.019	.003	-6.165	.000	-.026	-.013	.017
Parental/Gui- dance	.290	.108	2.681	.007	.078	.502	.003
Chronic Ill- ness	.089	.075	1.188	.235	-.058	.236	.001
Female	.477	.089	5.368	.000	.303	.652	.013
Lives with Partner	.141	.097	1.457	.145	-.049	.331	.001
College Education	.274	.108	2.537	.011	.062	.486	.003
Health Insurance	.684	.131	5.235	.000	.428	.940	.012
White	.193	.099	1.949	.051	-.001	.387	.002
Income	.644	.102	6.300	.000	.444	.845	.018
Unconcerned	-.483	.224	-2.152	.032	-.923	-.043	.002
Untroubled	-.153	.257	-.597	.551	-.656	.350	.000
Noncommittal	-.148	.311	-.477	.634	-.757	.461	.000

Cautious	.205	.288	.712	.477	-.360	.771	.000
Alarmed	.322	.297	1.084	.279	-.260	.904	.001
Concerned	0 <sup>a</sup>	.	.	.	.	.	.

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*Note.* a = This parameter is set to zero because it is redundant.

Table 5

*Logistic Regression Analysis of Information Sharing*

	B (SE)	95% Confidence Interval for Exp (B)		
		Exp (B)	Lower Bound	Upper Bound
<u>Included</u>				
Constant	-5.78(.80)***	.00	-	-
Patient Group	.13 (.05)*	1.14	1.03	1.26
Internet Use	3.17 (.72)***	23.84	5.78	98.35
Age	-.02 (.01)**	.98	.97	.99
Chronic Illness	.23 (.09)*	1.26	1.05	1.51
Female	.56 (.17)**	1.75	1.26	2.43
College	.20 (.18)	1.23	.86	1.75
Health Insurance	.71 (.27)*	2.03	1.19	3.48
Income	-.12 (.17)	.89	.63	1.24
White	-.13 (.18)	.62	.88	1.24

Note.  $R^2 = .05$  (Cox & Snell),  $.12$  (Nagelkerke). Model  $\chi^2 (5, N = 214) = 12.5, p < .01^*$ ,  $p < .001^{**}$ ,  $p < .000^{***}$ .

Table 6

*Logistic Regression Analysis of Support Seeking*

	95% Confidence Interval for Exp (B)			
	B (SE)	Exp (B)	Lower Bound	Upper Bound
<b>Included</b>				
Constant	-2.74 (.78)***	.06	-	-
Patient Group	.17 (.04)***	1.19	1.09	1.30
Internet Use	1.05 (.73)	2.87	.69	12.01
Age	-.04 (.01)***	.96	.95	.97
Chronic Illness	.13 (.09)	1.14	.96	1.36
Female	.47 (.15)**	1.60	1.21	2.13
College	.29 (.16)	1.34	.98	1.82
Health Insurance	.46 (.22)	1.59	1.02	2.45
Income	.23 (.16)	1.25	.93	1.70
White	.25 (.16)	1.29	.94	1.77

Note.  $R^2 = .05$  (Cox & Snell),  $.09$  (Nagelkerke). Model  $\chi^2 (5, N = 295) = 29.1, p < .01^*$ ,  $p < .001^{**}$ ,  $p < .000^{***}$ .

Table 7

*Summary of Findings*

	CONTROL	SIGNALED	TRIGGERED
	No Health Change or Emergency	Experienced Health Change	Experienced Emergency
Without Pre-Existing Health Condition	Unconcerned Group	Noncommittal Group	Alarmed Group
			<i>High Information Seeking</i>
With Pre-Existing Health Condition	Untroubled Group	Cautious Group	Concerned Group
		<i>High Information Seeking High Sharing High Support Seeking</i>	<i>High Sharing</i>

---

Figure 1

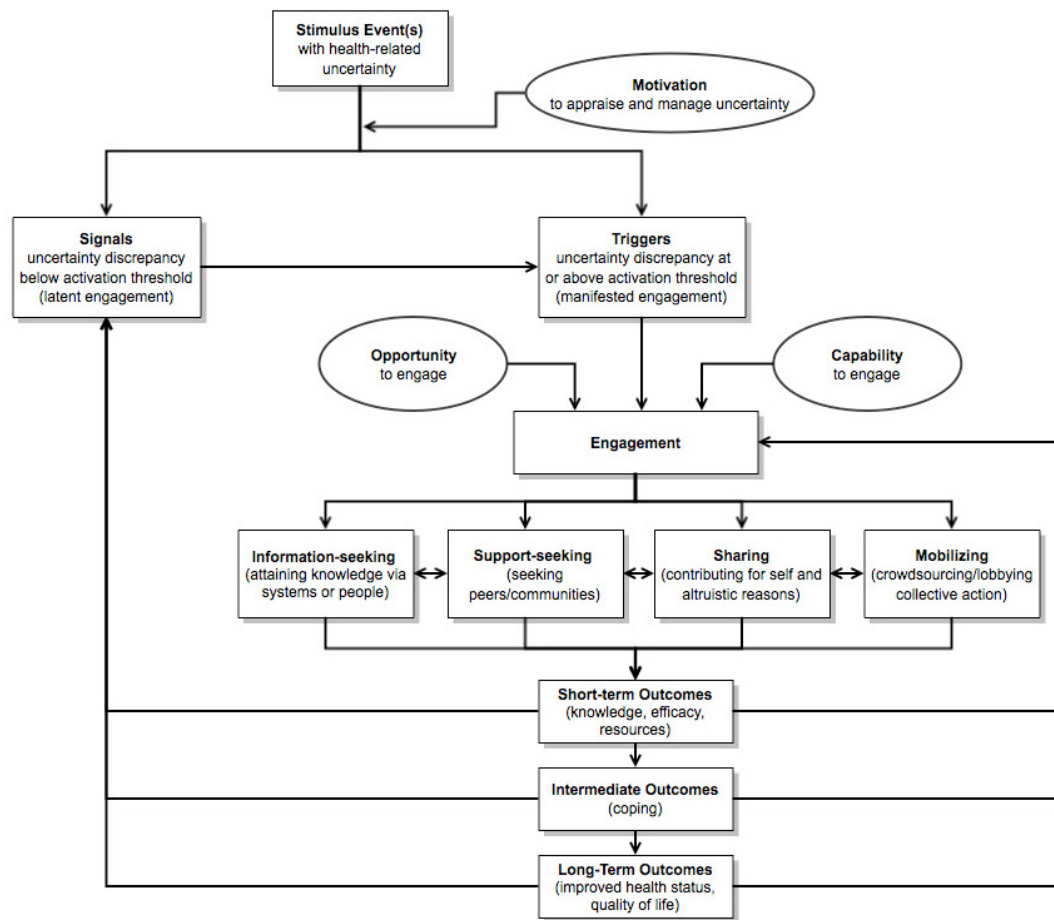


Figure 1. Conceptual model of patient engagement.

Figure 2

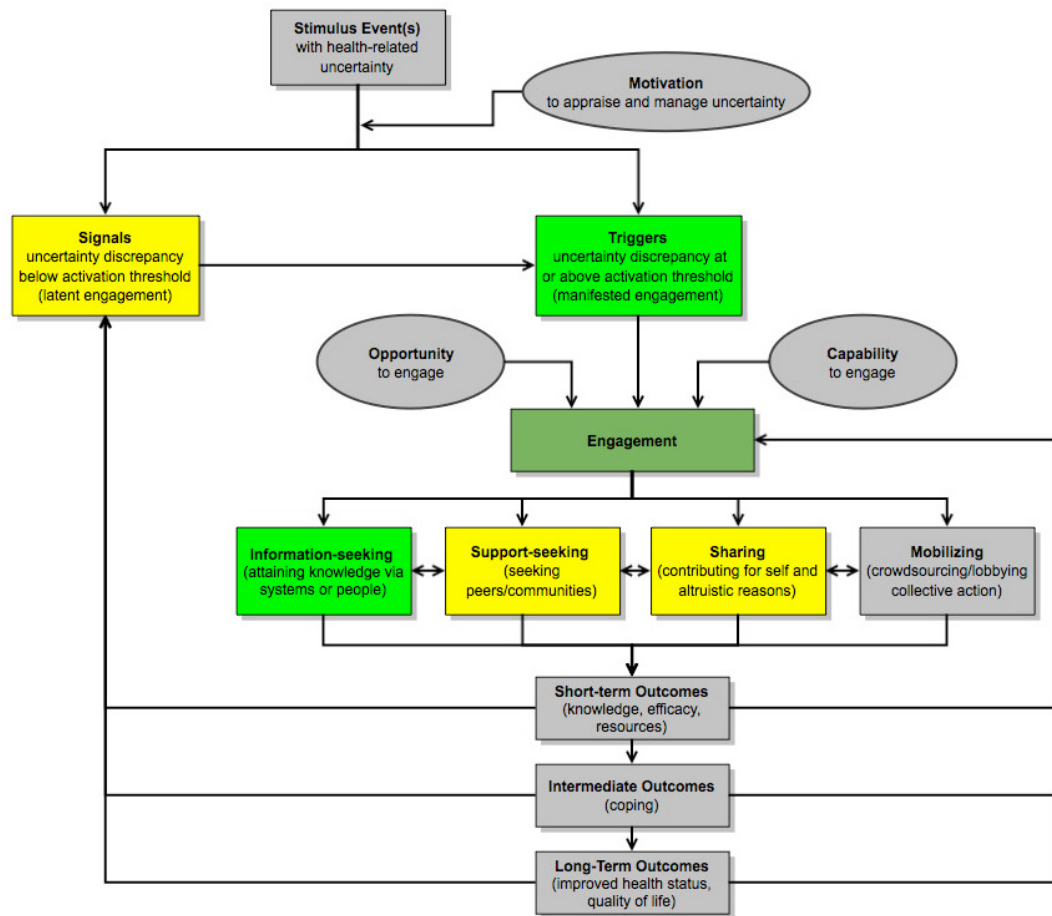
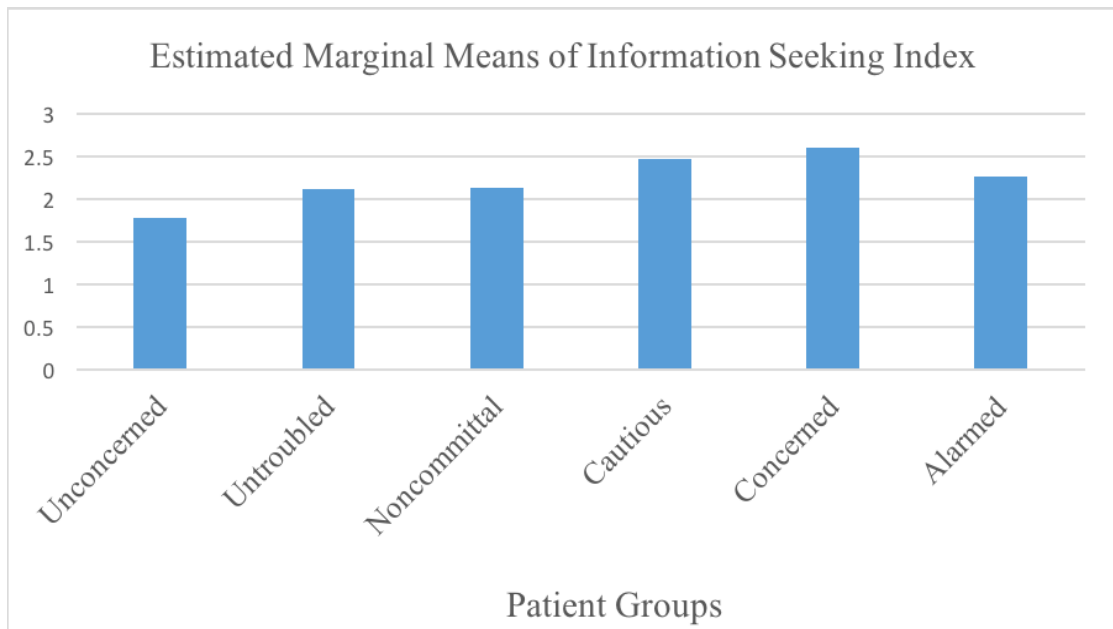


Figure 2. Empirical test of patient engagement model.

Figure 3



*Figure 3.* Confounder-Adjusted Mean comparisons of information seeking by patient group.



Appendix A  
Selected Items from Health Tracking Survey 2012

Princeton Survey Research Associates International

for the Pew Research Center's Internet & American Life Project

**I. Trigger Events with Severe Uncertainty Discrepancies**

**1. In the last 12 months, have you personally...[INSERT ITEMS IN ORDER]?**

	YES	NO	DON'T KNOW	REFUSED
<b>a. Faced a serious medical emergency or crisis<sup>2</sup></b>				
Current	11	89	*	*
September 2010	12	88	*	*
<b>b. Gone to the emergency room or been hospitalized unexpectedly</b>				
Current	17	83	*	*

**II. Signal Events with Mild Uncertainty Discrepancies**

**2. In the last 12 months, have you personally...[INSERT ITEMS IN ORDER]?**

<b>a. Experienced any significant change in your physical health, such as gaining or losing a lot of weight, becoming pregnant, or quitting smoking<sup>3</sup></b>				
Current	18	81	*	*
September 2010	17	83	*	*

**3. Are you now living with any of the following health problems or conditions?**

	YES	NO	DON'T KNOW	REFUSED
<b>a. Diabetes or sugar diabetes</b>				
Current	11	88	*	*
September 2010	11	89	*	*

<sup>2</sup> In September 2010, question was asked as a standalone question. For December 2008 and earlier, trend question wording was: "And in the last 12 months, have you or has someone close to you faced a serious medical emergency or crisis?"

<sup>3</sup> In September 2010, question was asked as a standalone question with the following question wording: "And in the last 12 months, have you experienced any other significant change in your physical health, such as gaining or losing a lot of weight, becoming pregnant, or quitting smoking?"

December 2008	10	90	*	1
<b>b. High blood pressure</b>				
Current	25	74	1	*
September 2010	24	75	1	*
December 2008	23	76	1	1
<b>c. Asthma, bronchitis, emphysema, or other lung conditions</b>				
Current	13	86	*	*
September 2010	12	88	*	*
December 2008	12	87	*	1
<b>d. Heart disease, heart failure or heart attack</b>				
Current	7	92	*	*
September 2010	6	94	*	*
December 2008	7	92	1	1
<b>e. Cancer</b>				
Current	3	96	*	*
September 2010	2	97	*	*
December 2008	3	96	1	1
<b>f. Any other chronic health problem or condition I haven't already mentioned</b>				
Current	16	83	*	*
September 2010	17	82	*	1

### III. Engagement Variable: ICTs as Sources of Information

**4. Please tell me if you ever use your cell phone to do any of the following things. Do you ever use your cell phone to [INSERT ITEMS]?<sup>4</sup>** Based on cell phone owners

	YES	NO	DON'T KNOW	REFUSED
<b>a. Look for health or medical information online<sup>5</sup></b>				
Current	31	69	*	*
April 2012	24	76	*	0
September 2010	17	83	*	0

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<sup>4</sup> In May 2011, the question was asked of all Form B cell phone owners and Form A cell phone owners who said in CELL7 that they do more than make calls on their phone. The percentages shown here are based on all cell phone users, counting as “no” Form A cell phone owners who said in CELL7 they use their phones only for making calls. Prior to May 2011, question was asked of all cell phone owners. Prior to January 2010, question wording was “Please tell me if you ever use your cell phone or Blackberry or other device to do any of the following things. Do you ever use it to [INSERT ITEM]?” In January 2010, question wording was “Please tell me if you ever use your cell phone or Blackberry or other handheld device to do any of the following things. Do you ever use it to [INSERT ITEMS]?” For January 2010, December 2009, and September 2009, an answer category “Cell phone can’t do this” was available as a volunteered option; “No” percentages for those trends reflect combined “No” and “Cell phone can’t do this” results.

<sup>5</sup> In April 2012, question was asked of cell phone owners who use the internet or email on their cell phone or download apps to their cell phone [N=953]; results are re-percentaged on all cell phone owners. In September 2010, question was a standalone question with the following question wording: “Do you ever use your cell phone to look up health or medical information?”

**5. Did you interact with them ONLINE through the internet or email, OFFLINE by visiting them in person or talking on the phone, or BOTH online and offline?<sup>6</sup>**

	YES, ON- LINE	YES, OFF- LINE	YES, BOTH	NO, NOT A SOURCE	DON'T KNOW	REFUSED
<b>a. A doctor or other health care professional</b>						
Current	1	61	8	28	1	1
September 2010	1	66	4	29	*	*
<b>b. Friends and family</b>						
Current	1	39	20	39	*	1
September 2010	1	42	12	44	1	*
<b>c. Others who have the same health condition</b>						
Current	2	15	7	73	1	1
September 2010	1	16	4	77	2	*

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<sup>6</sup> September 2010 question wording was slightly different: “Thinking about the LAST time you had a health issue, did you get information, care or support from... [INSERT; RANDOMIZE]? [IF YES AND INTERNET USER: Did you interact with them ONLINE through the internet or email, OFFLINE by visiting them in person or talking on the phone, or BOTH online and offline?]”

**6. Now, we'd like to know if you've looked for information ONLINE about certain health or medical issues, either for yourself or someone else. Specifically, in the last 12 months, have you looked online for information about... [INSERT FIRST ITEM; ASK a-b FIRST IN ORDER THEN RANDOMIZE c-k; ITEM L ALWAYS LAST]? In the last 12 months, have you looked online for information about... [INSERT NEXT ITEM]?<sup>7</sup>**

Based on all Internet users [N=2,392]

	YES, HAVE DONE THIS	NO, HAVE NOT DONE THIS	DON'T KNOW	REFUSED
<b>a. A specific disease or medical problem</b>				
Current	55	44	*	*
<b>b. A certain medical treatment or procedure</b>				
Current	43	56	*	*
<b>c. Health insurance, including private insurance, Medicare or Medicaid</b>				
Current	25	75	*	*
<b>d. Pregnancy and childbirth</b>				
Current	12	88	0	*
<b>e. Food safety or recalls</b>				
Current	19	80	*	*
<b>f. Drug safety or recalls</b>				
Current	16	84	*	*
<b>g. Medical test results</b>				
Current	15	85	*	*
<b>h. How to lose weight or how to control your weight</b>				
Current	27	73	*	*
<b>i. How to reduce your health care costs</b>				
Current	11	89	*	*

<sup>7</sup> Prior to the current survey, question wording was: "Now, we'd like to ask if you've looked for information ONLINE about certain health or medical issues. Specifically, have you ever looked online for... [INSERT ITEM]?" List of items may vary from survey to survey. The phrase "in the last 12 months" was added in the 2012 survey.

<b>j. Caring for an aging relative or friend</b>				
Current	14	86	*	*
<b>k. A drug you saw advertised</b>				
Current	16	84	*	*
<b>l. Any other health issue</b>				
Current	20	79	*	*
Total yes to any item above	72			
Total no to all items	28			

**7. Apart from looking for information online, there are many different activities related to health and medical issues a person might do on the internet. I'm going to read a list of online health-related activities you may or may not have done in the last 12 months. Just tell me if you happened to do each one, or not. (First,) in the last 12 months, have you... [INSERT ITEM; RANDOMIZE]? In the last 12 months, have you...[INSERT ITEM]?**

	YES	NO	DON'T KNOW	REFUSED
<b>a. Read or watched someone else's commentary or personal experience about health or medical issues online</b>				
Current internet users	26	74	*	*

**8. Thinking again about health-related activities you may or may not do online, have you... [INSERT ITEM]?<sup>8</sup>**

	YES	NO	DON'T KNOW	REFUSED
<b>a. Consulted online rankings or reviews of doctors or other providers<sup>9</sup></b>				
Current internet users [N=2,392]	17	83	*	*
Sept 2010 internet users [N=2,065]	16	84	0	*
<b>b. Consulted online rankings or reviews of hospitals or other medical facilities<sup>10</sup></b>				
Current internet users	14	86	*	0
Sept 2010 internet users	15	85	0	*
<b>c. Consulted online reviews of particular drugs or medical treatments</b>				

<sup>8</sup> Current question was asked of all internet users. September 2010 trend question was also asked of all internet users, with items asked in rotated order. December 2008 trend question was asked of online health seekers, with the following question wording: "There are many different activities related to health and medical issues a person might do on the internet. I'm going to read a list of things you may or may not have ever done online related to health and medical issues. Just tell me if you happened to do each one, or not. Have you... [INSERT ITEM; ROTATE]?"

<sup>9</sup> December 2008 trend item wording was "Consulted rankings or reviews online of doctors or other providers"

<sup>10</sup> December 2008 trend item wording was "Consulted rankings or reviews online of hospitals or other medical facilities"

Current internet users	18	82	1	*
Sept 2010 internet users	24	76	*	*

#### **IV. Engagement Variable: Interpersonal Networks as Sources of Information**

**9. Thinking about the LAST time you had a serious health issue or experienced any significant change in your physical health... Did you get information, care or support from... [INSERT ITEM; RANDOMIZE]? [IF YES AND INTERNET USER:**

	YES, ON- LINE	YES, OFF- LINE	YES, BOT H	NO, NOT A SOURC E	DON'T KNO W	REFUSED
<b>a. A doctor or other health care professional</b>						
Current	1	61	8	28	1	1
September 2010	1	66	4	29	*	*
<b>b. Friends and family</b>						
Current	1	39	20	39	*	1
September 2010	1	42	12	44	1	*
<b>c. Others who have the same health condition</b>						
Current	2	15	7	73	1	1
September 2010	1	16	4	77	2	*

#### **V. Engagement Variable: Support-Seeking**

**10. Apart from looking for information online, there are many different activities related to health and medical issues a person might do on the internet. I'm going to read a list of online health-related activities you may or may not have done in the last 12 months. Just tell me if you happened to do each one, or not. (First,) in the last 12 months, have you...**

<b>a. Gone online to find others who might have health concerns similar to yours</b>	YES	NO	DON'T KNOW	REFUSED
Current internet users	16	84	*	



## VI. Engagement Variable: Sharing

### 11. Still thinking just about the last 12 months, have you posted a health-related question online or shared your own personal health experience online in any way?

Based on all Internet users [N=2,392]

	<u>CURRENT</u>	
%	8	Yes
	92	No
	*	Don't know
	0	Refused

### 12. And what was it that you posted or shared online? Was it a specific QUESTION about your health, a COMMENT or STORY about your personal health experience, or BOTH a question and a comment?

Based on Internet users who have posted about a health topic or shared a health experience online [N=173]

	<u>CURRENT</u>	
%	19	Specific health question
	40	Comments/Stories about personal health experiences
	38	Both
	2	Neither/Something else (VOL.)
	1	Don't know
	0	Refused

### 13. Thinking again about health-related activities you may or may not do online, have you...

	<u>YES</u>	<u>NO</u>	<u>DON'T KNOW</u>	<u>REFUSED</u>
<b>a. Posted a review online of a doctor</b>				
Current internet users	4	96	0	0
Sept 2010 internet users	4	95	0	*
<b>b. Posted a review online of a hospital</b>				
Current internet users	3	97	*	*
Sept 2010 internet users	3	97	0	*
<b>c. Posted your experiences with a particular drug or medical treatment online</b>				
Current internet users	3	97	*	0
Sept 2010 internet users	4	96	0	*

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