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**Defining, Conceptualizing, and Measuring Health Literacy as a  
Necessary Step Towards Improved Health Outcomes:  
A Focus on Skills Needed to Find Health Information**

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A Focus on Skills Needed to Find Health Information**

**by**

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**Defining, Conceptualizing, and Measuring Health Literacy as a  
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The University of Texas at Austin, 2015

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Abstract: Health literacy is an individual's ability to find, understand, use, and communicate about health information in an effort to make informed health decisions. Low health literacy is prevalent in the U.S., where an estimated one-third of adults are thought to have difficulty with health information; however, this is more prevalent among racial/ethnic minorities, those who did not finish high school, and older adults. Low health literacy is thought to predict poor health, which results in billions of dollars in healthcare expenditures annually. Despite the prevalence of and concerns related to low health literacy, existing frameworks and measures are incapable of capturing changes in health literacy. As such, the purpose of this dissertation was to develop a conceptual model based on an existing definition of health literacy. This four-facet approach depicts health literacy as a latent variable comprised of the four skill sets included in the definition. A two-phase study was created to determine the skills needed for an individual to successfully find health information, the first facet included in the four-facet approach. Patients and health professionals (N=40) were asked about the skills they thought were needed to find health information (Phase One). Through these interviews, seven skills themes emerged (Knowing When to Search, Credibility Assessments, Reading Ability,

Finding Numerical Information, Interpersonal Seeking, Finding Health Information Online, and Spatial Navigation). Based on themes elicited in these interviews, a tool was created to measure items for each of these themes (Phase Two). This tool was administered through an online survey (N=331). Exploratory factor analysis was conducted to extract factors from Phase Two data. Phase Two factor data added that patients may need skills to scan paragraphical text (Text Within Text) and to extract information from nutrition labels (Labels) or from information with high amounts of medical jargon (Health Information Challenges). This two-phase methodological approach should be used in future studies to address the other three facets of health literacy. Ultimately, this will result in a measurement tool capable of reflecting changes in health literacy over time and areas in which intervention work is needed to produce improved health outcomes.

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## **1.0 INTRODUCTION**

Perhaps the most commonly accepted definition of health literacy is “The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Nielsen-Bohlman, Panzer, & Kindig, 2004; Ratzan & Parker, 2000). Individuals have different levels of health literacy, where those who struggle with the aforementioned capacities are seen as having “low health literacy.” Low health literacy is a prevalent health concern in the U.S. where an estimated one out of three American adults experiences challenges when interacting with health information (Kutner, et al., 2006; Paasche-Orlow et al., 2005; Williams et al., 1995). However, low health literacy is more prevalent in individuals who did not complete high school, racial/ethnic minorities, and the elderly (Nielsen-Bohlman et al., Paasche-Orlow & Wolf, 2007); groups who are already at risk for a number of health concerns.

The prevalence of low health literacy is especially worrisome given the many negative effects it has on health decisions and outcomes. Overall, low health literate individuals are thought to have poorer health (IOM, 2009; Nielsen-Bohlman et al., 2004). Indeed, a systematic review of health literacy literature points to a number of relationships between low health literacy and poorer health including a decreased use of preventive services (such as getting cancer screenings), a greater rate of hospitalizations and emergency room visits, and a decreased ability to adhere to prescription medication instructions or understand similar health messages (Berkman et al., 2011). Some suggest

that health literacy is related to health outcomes but is mediated by environmental factors such as an individual's interaction with their healthcare provider and the complexity of the healthcare system (Paasche-Orlow & Wolf, 2007). However, healthcare providers tend to not measure the health literacy of their patient (Ryan et al., 2008), and thus may not recognize those with low health literacy.

Low health literate patients also report difficulty in understanding and communicating with their healthcare providers (Williams et al., 2002), are more likely to engage in limited health information searches, if at all, and report avoiding “.gov” and “.edu” websites (Mackert et al., 2009). Finally, individuals with low health literacy exhibit greater hopelessness and may be less likely to visit a doctor for critical health concerns such as cancer (Morris et al., 2013) and have a more difficult time discussing health procedures with specialists such as radiologists (Smith et al., 2014). These challenges cost the U.S. economy an estimated \$106 billion annually. This estimate is thought to increase if we do not promote greater effort to understanding health literacy (Vernon et al., 2007).

It is no wonder why efforts in research and practice have recently expanded in the area of health literacy. It is clear that this concept is a critical opportunity for understanding and promoting patient health. Although health literacy is undeniably an important factor for health communication and outcomes, there are some critical concerns that surround this concept.

First, as it stands currently, there is no commonly *accepted* definition of health literacy (Baker, 2006; Berkman, Davis, & McCormack, 2010; Sorensen et al., 2012). The

definition given at the opening of this piece may be that which is most commonly used, but it falls far from being widely accepted across fields of practitioners and researchers. Perhaps as a result of this limitation, health literacy is also thought to lack a measure or a theoretical framework that truly reflects this concept. These challenges contribute to an “unstable” body of literature (Pleasant, McKinney, & Rikard, 2011, p11) and place limitations on generating effective interventions that could increase health literacy and vital health outcomes.

Without first establishing an accepted definition of health literacy, as well as a supportive measure and framework, it is difficult to build a body of truly meaningful health literacy evidence. Specifically, it is challenging to build intervention work that improves health literacy skills of patients if we are unsure of both what these skills are and how to measure them. The existing state of health literacy can only scratch the surface of the mechanisms through which health literacy contributes to better health. This is hardly acceptable if we are to improve patient health.

The purpose of this paper is to first explicate the concept of health literacy. The proposals made in this paper are thought to contribute one perspective on health literacy and are meant to be part of a conversation on this topic, rather than a definitive solution to the challenges this concept currently faces. There have already been numerous attempts to develop a concrete definition of health literacy without much agreement, yet we continue to plow forward, continuing to witness fragmentation in this important area of research (Pleasant, McKinney, & Rikard, 2011; Mackert et al., in press; Haun et al., 2014). It is important to engage in interdisciplinary conversations on this topic as health

literacy involves many parties including patients, healthcare providers, family and friends, and the media.

In the sections that follow, I will first address how the concept of health literacy has evolved since its conception, especially in the areas of defining and measuring this concept. Then, given a review of the existing literature, suggestions for future efforts in these areas of health literacy will be made, including the description of a new health literacy framework that outlines health literacy as being comprised of four key facets or constellations of skills: Finding, understanding, using and communicating about health information. This will be followed by exploratory research from a recent study in which an instrument was created to capture patient skills for finding health information; the first health literacy facet. The development and findings from this study are meant to serve as a model for creating future instruments that capture the other facets of health literacy. Given the relationship between patient health literacy and health outcomes, it is important to explore this concept further so that effective interventions can be developed.

## **2.0 LITERATURE REVIEW**

### **2.1 EARLY WORK IN HEALTH LITERACY**

Determining a definition for “health literacy” might have been doomed from the start. Those not familiar with this term may apply the well-known “literacy” term directly to health materials, resulting in the assumption that health literacy is only an individual’s ability to read health texts. Indeed, it is thought that health literacy emerged from the larger concept of general literacy (Berkman et al., 2010), which went through a number of conceptual transformations itself. Even in today’s research, “literacy” is thought to be many things including: a skill set, a practical group of “functions” or applied behaviors, a process, and as what is presented in printed materials (Sorensen et al., 2012). Sorensen and colleagues argue that these different definitions have also been applied to health literacy. Given its birth from literacy, a concept that varied in definition throughout the years, finalizing a definition of health literacy was always likely going to be a challenge.

However, it may be that our country’s fascination with measuring education and literacy is responsible for shifting some attention toward health literacy. A nationally representative assessment of general literacy conducted by the U.S. Department of Education, the National Adult Literacy Survey (NALS), was created to “assess the breadth and depth of adult literacy in the entire population” (Sorensen et al., 2012, p11). Results from this general literacy assessment (conducted in 1993) suggested that an alarming proportion of Americans, roughly one-quarter to one-half, had marginal or low literacy skills (Ad Hoc Committee on Health Literacy, 1999). In response to these

findings and the growing literature that supported a relationship between low general literacy and poorer health outcomes (Ad Hoc Committee on Health Literacy), specific effort was attributed to examining *literacy* within the *context of health* (Sorensen et al.). One example of this was the emergence of the first measure of “health literacy,” the Rapid Estimate of Adult Literacy in Medicine (REALM), which involves having patients pronounce a list of medical-oriented words (e.g., “arthritis,” “appendix”) (Davis et al., 1991; Davis et al., 1993). Indeed, the REALM represents what some would typically conceptualize as health literacy – one’s reading ability in a health context.

A NALS follow up, the National Assessment of Adult Literacy Survey (NAAL), took place in 2003 and was the first (and continues to be the *only*) true nationally representative measure of health literacy in the U.S. The NAAL included an explicit nod to health literacy by capturing individual’s “prose literacy” (defined as “continuous text”), “document literacy” (defined as “non-continuous text”), and “quantitative” skills in three areas related to health tasks, “clinical” (e.g., actions taking place in a healthcare setting such as patient-provider communication), “prevention” (e.g., behaviors related to maintaining good health), and “navigation of the healthcare system” (Kutner et al., 2006, p.iv, 2-3). Inclusion of these items on the NAAL was a response to a call from *Healthy People*, which requested the addition of items thought to reflect one’s literacy in health (Berkman et al., 2010). Findings from this large-scale study were alarming; only 12% of the American adult population exhibited “proficient” health literacy and only 53% were thought to have “intermediate” health literacy (Kutner et al.).



NAAL represents not only an important milestone in the history of health literacy, but it continues to serve as the only truly nationally representative dataset on health literacy; thus, it is often cited for the prevalence of health literacy in the U.S. and as a comparative basis for many current health literacy studies. It is likely that NAAL facilitated the attention given to the study of health literacy that we see today. Because of the existing limitations in the health literacy prevalence data, there has been a recent surge of research and conversation dedicated to how health literacy should be defined, conceptualized, and measured. These are important initial steps that must be taken to move forward in the process of creating effective health literacy intervention programs.

## **2.2 HEALTH LITERACY: PROBLEMS WITH DEFINITION, CONCEPTUAL MODELS, MEASUREMENT**

### **2.2.1 Fragmentation in Definition**

Given the importance and strengths of NAAL, the definition used to generate this study was clearly the forerunner for outlining what health literacy “was,” at least at the time. NAAL employed the definition stated at the opening of this paper, which was originally generated by Ratzan and Parker (2000) for a section of the U.S. Department of Health and Human Service’s *Current Bibliographies in Medicine*. This definition continues to be widely used; it is the definition that appears on the National Institutes of Health NIH (NIH, 2014) and Centers for Disease Control and Prevention CDC (CDC, 2014) pages on health literacy.

However, few agree on what health literacy actually “is;” as evidenced by a wide variety of definitions utilized by researchers and practitioners. Systematic literature

reviews aimed at finding a definition of health literacy uncovered 13 (Berkman et al., 2010) and 17 (Sorensen et al., 2012) different conceptualizations, which can be reviewed in their respective publications. As a result of reviewing these definitions, each of these systematic efforts generated new definitions based on their evaluation:

Health literacy is the degree to which individuals can obtain, process, understand, and communicate about health-related information needed to make informed health decisions (Berkman et al., 2010).

This definition suggests only a slight departure from the prominent Ratzan and Parker (2000) definition. However, an important addition made to this definition is the inclusion of a communication element. It is important to consider not just how individuals go about reading and understanding health information, but they must also be able to communicate about health, whether it be through asking questions, explaining symptoms in the healthcare system or providing and discussing health information with friends and family. Communicating about health information is a large and growing body of literature and should be included in the definition of health literacy; yet, no other element of the existing Ratzan and Parker definition suggests that individuals might communicate with others in an effort to get this information.

Another definition of health literacy that comes from extensive review of existing definitions is that from Sorensen and colleagues:

Health literacy is linked to literacy and entails people's knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning

healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course (Sorensen et al., 2012).

In contrast to the previous definition from Berkman and colleagues, which focuses on updating an existing definition, the Sorensen et al. definition aims to incorporate elements from the many definitions uncovered in their review. Some of the elements in this definition are perhaps unnecessary such as “healthcare, disease prevention, and health promotion” which can be summarized simply as “health,” as described by Berkman et al.

The reviews of health literacy definitions by Berkman and Sorensen (and their respective colleagues) shed light on the extent of the fragmentation seen in the conceptualization and definition of health literacy. Unfortunately, having a consistent understanding of what health literacy “is” is not limited to definition alone.

### **2.2.2 Lack of Conceptual Models**

The problems seen in defining health literacy are also clear in the existing conceptual models and frameworks designed to depict health literacy. Unfortunately, the existing models may be seen as “kitchen sink” models; they include a variety of variables and are not conducive to model testing. Creators of these models even admit that testing some of the concepts would be “impractical” (Baker, 2006, p880). In reviewing these conceptual models, the input (factors that impact health literacy) and the output (factors influenced by health literacy) are clear; however, what remains a mystery in these models is what health literacy *is*. In these models health literacy is typically pictured as just one “health literacy” box. What does the box represent? What are the mechanisms it contains? If we are to better understand health literacy and the relationship it shares with

health so that we can create more effective interventions that improve this concept, we need to understand what is in that box.

### **2.2.3 Health Literacy Screening as Measurement**

Finally, the measurement of health literacy echoes similar problems seen in defining and illustrating this concept. Measurement issues might be seen as easily improvable where items can be added, deleted, and adapted, but health literacy measurement can only be determined after a consistent definition of health literacy is produced. There exist a number of specific calls to improve health literacy measurement (IOM, 2009), as none of the current measures truly reflect the current definition of health literacy, among other limitations.

In addition to measurements made through NAAL and the aforementioned REALM, several measures of general health literacy have developed in recent years. The Test of Functional Literacy in Adults (TOFHLA) requires participants to read health-related passages and complete fill-in-the-blank type questions for both words and numbers (Parker et al., 1995). There is also a short form version of the TOFHLA (S-TOFHLA), which consists of four numeracy items and two reading passages in contrast to the longer seven numeracy items and three reading passages used in the TOFHLA (Baker et al., 1999). Individuals are awarded points for correct answers to the TOFHLA items, where the highest attainable score is a 100 and the lowest, with no questions answered correctly, is a score of zero. A score of 75 and higher is said to reflect adequate health literacy.

Another commonly used measure of general health literacy is the Newest Vital Sign (NVS) (Weiss et al., 2005). This measure consists of six numeracy and reading questions that address a nutrition label said to come from the back of a container of a pint of ice cream. This visual stimulus (nutrition label) is an example of a piece of health information for which the general population encounters on a regular basis and requires viewers to find and use the information to answer the health literacy questions. Similar to the TOFHLA, individuals are awarded points when they answer these questions correctly. Participants receive one point for each question they answer correctly and a score of 4 or higher (4-6 questions answered correctly) is thought to reflect “adequate” health literacy, whereas a score between 0 and 3 may reflect less than adequate health literacy (Weiss et al.). The NVS typically takes less than three minutes to administer (Ciccarelli Shah et al., 2010) and has shown to not cause stress or perceived stigma in patients (VanGeest, Welch, & Weiner, 2010).

Given that these items were generated for use with low literate patients, these measures (REALM, TOFHLA, S-TOFHLA, NVS) must be administered orally, which requires time and resources from healthcare staff. Although these are often viewed as measures of general health literacy, in the Institute of Medicine’s (IOM) *Workshop Summary on Measures of Health Literacy* (IOM *Workshop Summary*), Pleasant argues that these measures should rather be seen as “screening items,” which may categorize an individual as having either adequate or less than adequate health literacy but sheds little light on the reasons why one is categorized one way or the other. Pleasant suggests that

measurement should instead contribute to the understanding of the concept, including explanations of structure, function, and effectiveness (IOM, 2009).

It is also important to note that, in response to the call for improved health literacy measurement, there has been a subsequent boom of measures added to this body of work. For example, a recent review of health literacy measurement instruments published in PsychINFO and PubMed between 1999 and 2013 revealed 51 different tools available (Haun et al., 2014). Rather than improving on the existing measures or creating measures that are reflective of the definition of health literacy, many of the newly added measures (15 of the 51 tools reviewed by Haun et al.) are “domain-specific” – they address health literacy within a specific health context. Examples of this include mental health (Jorm, 2000), oral health (Naghbi Sistani et al., 2013), and diabetes (Yamashita & Kart, 2011) health literacies. One example of domain specific health literacy items might include an individual’s capacity for finding, understanding, using, and communicating specifically about oral health-related information. Arguably, examining health literacy in these contexts does not add anything new to a body of knowledge of health literacy; health literacy is thought to traverse all health contexts – if a person is challenged by finding oral health information, it is likely that they will experience difficulty in finding similar information on diabetes rather than the disease context creating new challenges for that person. Similar measures have been created to measure health literacy within specific populations such as patients of different ages (10 of the 51 tools reviewed by Haun et al.). Additionally, in creating new and specific measures for individual health contexts and populations, comparison of findings across these studies is not possible. This severely

constrains our ability to explore health literacy (Mackert et al., in press; Pleasant et al., 2011).

Participants in the IOM's *Workshop Summary* argue, "What gets measured, gets done." However, none of the currently available measures truly reflect existing definitions of health literacy. This could be a complication that stems from Pleasant's point about how these measures were not developed as true measures, but were rather created for the purpose of using in healthcare settings to determine whether or not a patient has low health literacy. Moreover, as much as there is going on with health literacy measurement – somehow there is simultaneously nothing going on – we continue to use population-based data from NAAL, which is over a decade old. We also continue to go without a population-level measure for health literacy (IOM, 2009), given the constraint of having to administer most measures orally; however, some efforts have been made in this arena including using existing items on nationally representative surveys such as the National Cancer Institute's (NCI) Health Information National Trends Survey (HINTS) (Champlin & Mackert, in press) and imputing demographic information (Hanchate et al., 2008).

Examining these health literacy challenges sheds light on areas that can be improved. In reading about the existing state of health literacy, you might already see some problems yourself or have questions about what is being done in specific areas to address these issues. I will now point to several questions raised by scholars and practitioners in the area of health literacy. The discussion of these questions will set the stage for the proposition of a new way of conceptualizing, defining, and measuring health

literacy, which may address some of these critical concerns. Then, a future study that begins to target these challenges will be introduced.

### **2.3 KEY QUESTIONS IN THE AREA OF HEALTH LITERACY**

There are a number of reoccurring questions and debates in the field of health literacy. These points may be central reasons for why there has been little progress in establishing a concrete conceptualization, framework, and measurement for health literacy. I will now address several of the points that gain extensive attention in the literature and at health literacy conferences. This is not meant as a definitive list of the arguments that exist in this area, nor are there direct answers to any of these points (yet). However, in outlining these questions we will have a better understanding of the concerns that emerge when focusing on what we currently know about the concept of health literacy.

1.) Should health literacy be considered an individual level factor or as something larger?

Currently, health literacy is thought to be an *individual's* capacity or skills for several tasks related to health information; however, it has been questioned that health literacy be “only” the responsibility of the individual. Instead, many suggest that health literacy should be defined as an interaction between an individual’s skills and the level of challenges presented in the environment, with a specific focus on the healthcare system. This suggestion is perhaps made most clear in the IOM’s *Workshop Summary* (2009, p11), “health literacy emerges when the expectations, preferences, and skills of individuals seeking health information and services meet the expectations, preferences, and skill of those providing information and services.” Arguments in support of this



health literacy conceptualization suggest that, given the many changes in the medical and economic systems in the U.S., navigation of these arenas has become highly complex; yet, individuals are also expected to take greater control over their personal health (Parker, Ratzan, & Lurle, 2003). Where does health literacy fall – at the responsibility of the individual, the healthcare system, or both?

In addition, there is extensive confusion as to what constitutes each side of this equation. Of greatest concern is what should constitute being “health literate” (Berkman et al., 2010). Berkman, Davis, and McCormack (2010) suggest that we initially focused on “skills” people needed to tackle health information, such as being able to read and listen. However, definitions of health literacy have shifted more in the direction of whether or not one can reach the “goals,” or have the capacities for finding, understanding, using, and communicating about health information. Is it important that we distinguish between these concepts and if so, is it a matter of choosing one over the other? Looking at the existing conceptual models of health literacy, there are numerous skills, abilities, and factors that we might think contribute to health literacy – how can we decide which of these are most important? This is especially difficult with a lack of a testable framework.

2.) Is health literacy a clinical concept, or public health, or something else?

Pleasant and Kuruvilla (2008) argue that, in addition to perhaps having feet in both individual and environmental camps, health literacy is also stretched across the areas of clinical and public health, each of which, they suggest, treats health literacy differently. A clinical approach to health literacy focuses on the skills and goals a patient

has for existing in the healthcare system such as whether they can understand prescriptions and communicate symptoms to their provider (Pleasant & Kuruvilla). In the *IOM Workshop Summary*, Pleasant additionally addresses this issue by pointing out that many of the existing measures of health literacy were designed for clinical settings (IOM, 2009). As such, health literacy may be thought to receive “too much” attention regarding clinical challenges and not enough of a focus on how health literacy also contributes to public health-related decisions.

The public health approach to health literacy instead focuses on global health promotion and health in the context of the “public sphere” (Pleasant & Kuruvilla, 2008 p153). In an effort to promote health literacy in a public health context, Pleasant and Kuruvilla generated a list of “Facts of Life” – health facts that everyone, regardless of age, education, or country, should know; for example, “Many diseases can be prevented by washing hands before touching food” (p156). This list is thought to be an initial attempt at representing a patient’s understanding of public health decisions in an arena thought to be dominated by clinically driven conceptualizations and measures of health literacy. In short, it is important that individuals not just think of how they will make personal decisions about finding, understanding, using, and communicating about health information, but they should also take into account the larger global sphere of public health (for example, health literacy should include an individual’s understanding of population-based health).

Health literacy has been conceptualized even more broadly than these clinical and public health contexts. For example, one model of health literacy suggests adding

science, civic, and cultural literacies (Zarcadoolas, Pleasant, & Greer, 2005). It is undeniable that these elements contribute to one's understanding of health and resulting decisions. An example drawn from this literature is that having an understanding of "science" and the scientific process allows one to better understand how health recommendations are made and how they are ever changing. It is important to consider these arguments in defining health literacy, but it is also necessary to weigh these benefits with the cost attached to challenges inherent in measuring all of these different facets. Similarly, as described in the previous section, others conceptualize health literacy within specific health contexts such as "diabetes" or populations such as "adolescents." Ultimately, it is important to determine the context, if any, in which health literacy should exist.

### 3.) Is health literacy a fixed construct or can it change over time?

Berkman, Davis, and McCormack (2010) argue that general literacy is fairly resistant to change in the absence of effective intervention work; yet they suggest that thinking of health literacy as an ever-changing concept is possible. In contrast, in interviews about what constitutes their "health journey," adults described health literacy as a dynamic process, which improves given greater experience interacting with health information (Begoray & Kwan, 2011). This question is a key focus for the future of health literacy, as changes in technology may improve the availability and accessibility of health information. Similarly, if we are to make improvements in the healthcare environment such as easier-to-read health information materials, will this have an impact on individual-level health literacy? It is suggested that we adapt our definitions and

measures to reflect what is “representative of the skills needed to function successfully in the current society” (Berkman, Davis, McCormack, p12).

To add to this discussion, it is also important to note that there has been little, if any, longitudinal evidence regarding health literacy. This may be a complication of our restricted health literacy measurement; for example, we do not yet have an understanding of what it takes to move an individual from a 3 to a 4 out of a total score of 6 on the NVS health literacy measure. More importantly, what does this increase in score mean, if anything? This is an area of research that needs explicit improvement.

These points are clear avenues for improving the definition of health literacy; they may seem obvious, but there has been little progress in improving the definition and measurement of health literacy since Baker first pointed to these problems almost ten years ago. One reason for this could be the concern that a definition of health literacy might contain too little or too much. Looking at the conceptual models currently available for health literacy suggests that we may be quick to add all of the factors into a model, with no concern for subsequent measurement. Others may be worried that too simple of a model would not do justice to this important construct. These problems are not exclusive to health literacy. Social determinants of health such as race/ethnicity, socioeconomic status, and education have also encountered considerable discussion on how to define, measure, and create frameworks that explain these factors’ relationship to health outcomes (Braveman, Egerter, & Williams, 2011). I will now propose one way of conceptualizing (and creating a subsequent model and measurement for) health literacy that might provide at least some response to the aforementioned suggestions for

improvement. This conceptualization of course has its limitations, which will also be addressed. This way of thinking about health literacy has been addressed in only limited literature previously.

## **2.4 HEALTH LITERACY MOVING FORWARD**

Rather than moving forward by adding complications and layers to the ongoing health literacy conversation, a key step in defining health literacy may be to take a step back: What *is* health literacy? It is important to resist the urge to throw in a bunch of variables that we know impact health outcomes in an effort to force them into health literacy. This point comes from a suggestion made by Ratzan at the IOM workshop on health literacy measurement, stating that “the field today [should] not become too epistemological or ontological on the issue of the definition of health literacy, resulting in the perfect becoming the enemy of the good” (IOM, 2009, p40-1). Indeed, the suggestions that follow are by no means “perfect;” they are just seen as one proposed way of defining and measuring health literacy that should be included in the conversation on this important issue. These conceptualization ideas have implications for understanding the mechanisms that are thought to drive health literacy.

### **2.4.1 Conceptualization**

A proposed method for conceptualizing health literacy is as a concept comprised of four unique capacities – finding, understanding, using, and communicating about health information – for which each facet utilizes a set of corresponding skills (Appendix A). As such, health literacy could be seen as a factor comprised of four central sets of

skills. In an effort to take a stance on the three health literacy questions introduced in the previous section (2.3), this conceptualization depicts health literacy as 1.) an individual level factor, 2.) relevant to all health contexts, and 3.) changeable over time. Although health literacy is often defined this way, it has not yet been conceptualized as distinct skill sets. It is thought that conceptualizing health literacy this way may show the greatest agreement with existing literature, which tends to treat patient health literacy as an individual-level factor (Berkman et al., 2010; Sorensen et al., 2012). Also, this conceptualization of health literacy will allow for extensive future use by not limiting to a specific context or population and being changeable over time (a central goal needed for the development of future health literacy interventions).

Having a skill reflects that an individual has the capacity to complete a specific activity (i.e. they have the ability to do something). As such, a skill does not include a valenced evaluation of an object (i.e. attitude), nor does it capture input or expectations from others outside the individual (i.e. norms). An individual can vary in how much of a specific skill they have (actual skill) or see themselves as having (perceived skill). In an effort to define the proposed conceptualization of health literacy, it is important to outline the skills needed for an individual to successfully 1.) find, 2.) understand, 3.) use, and 4.) communicate about health information.

Thought of this way, health literacy is seen as a latent construct – one that is reflected not through direct measurement, but indirectly through measurement of observed “skill” variables. To echo the thoughts of Pleasant, “one cannot “see” health literacy” (IOM, 2009, p21); however, one may be able to see, measure, and address the

health literacy skills. A depiction of this conceptualization is included in Appendix A, where underlying capacities are reflected through measurable skills.

Clearly this is not a drastic change in how health literacy is *defined*; in fact, this idea only suggests to “piece out” and examine the health literacy capacities as separate entities. As such, it offers more of a “way of thinking” about health literacy. Even though a majority of the definitions reviewed by Berkman and Sorensen suggest that health literacy is made up of these components, thinking of health literacy this way has been addressed in only limited literature. It seems that very few currently think of health literacy this way. The existing research in this area is now addressed.

In their development of the health literacy management scale (HeLMS), Jordan and colleagues sought to understand this construct from the perspective of the patient. They argue that this important voice should not be neglected in the conversation on what constitutes health literacy. The HeLMS is one health literacy measure that reflects health literacy as a *set* of distinct abilities, rather than focusing on literacy and numeracy skills only. Through interviews where patients were asked to discuss their “healthcare journey,” six capacities emerged from these conversations that were thought to interact with both individual and environmental factors such as the individual’s educational background and social support systems, respectively. These capacities include: knowledge of when and where to access health information, verbal communication skills, showing proactiveness towards health challenges, literacy skills, showing the capacity to retain and process information, and the ability to apply skills and information to health decisions (Jordan et al., 2013; Jordan, Buchbinder, & Osborne, 2010).

Begoray and Kwan (2011) conducted similar interviews with adults in an effort to discuss differences across the components of health literacy. Adults in this study indeed described a range of challenges and procedures they experience for finding, understanding, appraising, and communicating about health information. Likewise, when asked about which skills they saw themselves as having, many indicated that they had the skills to “ask others to clarify any health information that is unclear” and “pick out the health information they want;” however, fewer saw themselves as having the “skills to judge which health information can be trusted” and the “skills to make sense of health information that is inconsistent” (Begoray & Kwan, p28).

Results from these studies are important because they suggest that patients support the notion that the facets of health literacy indeed involve different processes and pose different benefits and barriers. However, in the aforementioned studies, health literacy is consistently re-defined given the responses from patients, rather than relying on the existing definitions of this concept. This method is most comparable to research that develops a new health literacy measure based on the demographics of independent samples (e.g., health literacy for people with breast cancer, health literacy for people with oral cancer). As such, a weakness of these approaches is that findings from each study may yield different health literacy facets given the population included in the study, rather than relying on an existing definition to frame the study. The framework depicted in Appendix A combines these two ideas: skills for each facet of health literacy likely vary for individuals and can be measured (as described by the research outlined above) and there currently exists a definition of health literacy that describes the concept as a



latent construct being comprised of four facets, yet there is no current conceptualization, framework, or measurement tool for this definition.

I will now outline the existing literature on one facet of health literacy, that of finding health information. This review serves as a basis for a study in this area of research. The goal of the study is to take a first step at translating the newly developed conceptualization, outlined in Appendix A, to a measured instrument capable of capturing the skills needed for each health literacy facet. Thinking about and measuring health literacy in this way could not only provide a framework for understanding what health literacy is but could also set the stage for intervention work by having a way of measuring health literacy skill set improvement over time. This “skills for finding health information” facet will be used as a platform or model for a series of future studies that aim to create similar skill set instruments that capture these remaining facets. A review of this literature is presented to point to areas that could help to inform the list of skills needed for success with this health literacy facet and provide context for what has been done in this area of research already.

#### **2.4.2 Finding Health Information**

The purpose of this study will be to determine the skills needed to find health information, and, after the skills are labeled, an instrument will be created that measures patient health information finding skills. Similar to the development of HeLMS (Jordan et al., 2013; Jordan, Buchbinder, & Osborne, 2010), an intention of this study is to include the input of patients to determine the skills required to find health information. A

review of the relevant literature in this area will help to inform an interview guide. Then, based on findings from interviews, the measurement instrument will be created.

This finding health information facet of health literacy was selected as the focus of the first study aimed at exploring the conceptualization in Appendix A because it may be that subsequent facets (understanding, using, and communicating about health information) may be less likely to occur if one has not first sought and found health information. Given the outline of health literacy in the previous sections, it is thought that the skills needed for finding health information drive the concept of health literacy, but are only one set of skills that contributes to this concept.

Finding information may be seen as the “goal” of the process of information seeking; however, information *seeking* is just one form of information management. Others include information provision and avoidance, as well as working to understand this information (Brashers, Goldsmith, Hsieh, 2002). As such, information seeking is thought to be a specific process in which an individual actively looks for information. This process assumes that the individual takes charge of these activities, rather than passively receiving, attending, and being impacted by messages to which they are exposed (Griffin, Dunwoody, & Neuwirth, 1999; Afifi & Weiner, 2004). This differentiation may be attributed to the shift in communication research, which took place in the late 1950s as a result of the development of Uses and Gratifications (U&G). U&G is a framework suggesting that individuals *do* something *with* media, rather than media only uni-directionally impacting its viewers (Katz, 1959; Armitage & Conner, 2001). Similarly, information seeking is different from topic avoidance in which individuals

actively steer clear of information on a topic or in a given area, potentially because the information could be frightening or intimidating (Brashers, Goldsmith, & Hsieh).

Thus, health information seeking is thought to be an active process in which an individual is motivated in some way to locate details about a health topic. This active process, although closely linked, is also inherently different from the skills one may possess that contribute to information seeking. For example, an individual may have the *skills* to find health information, but they do not engage in the search process. It is this skill set that contributes to health literacy; however, a review of the health information seeking literature may help to shed light on possible skills that may be utilized in the process of information seeking.

Generally, health information seeking behavior is seen as a unique, yet not fully understood concept. In their conceptual analysis of the topic, Lambert and Loiselle (2007) reveal several important challenges for determining the skills needed for finding health information specifically. First, they highlight that, while many researchers state that health information seeking does require particular skills different from general information seeking (i.e. not on health topics), it is unclear what the skills are. Based on their review of the literature, Lambert and Loiselle argue that health information seeking behavior may be comprised of two key factors: the concept of *information* (including the “type” of information sought and the “amount” of searching that takes place) and the concept of *method* (including the behaviors one might engage in to obtain information). This two-construct framework of health information seeking will be used to outline an initial list of skills that might be needed to engage in these efforts. Using these two

categories, information and method, as a starting point, we can begin to extract skills commonly found in several of the prevalent information seeking frameworks that match either of these topics.

The study of the information seeking process has grown in recent years and now includes a host of theoretical frameworks including Extended Parallel Processing Model (EPPM) (Witte, 1992), the Risk Information Seeking and Processing Model (RISP) (Griffin, Dunwoody, & Neuwirth, 1999), the Planned Risk Information Seeking Model (PRISM) (Kahlor, 2010), and others. Specifically, Griffin, Dunwoody, and Neuwirth (1999) hypothesized a number of variables that could influence whether an individual will engage in the behavior of information seeking. Two key factors, Knowing When to Search and Credibility Assessments, are most applicable to the skills needed to find health information. These are described below. In addition, existing health literacy research such as the NAAL suggests that other factors may play a critical role in an individual's ability to find health information. These include an individual's ability to find word and numerical information in written passages (Kutner et al., 2006). Still other research suggests that interpersonal communication skills may be a factor in how individuals get health information. These factors are also described below. Then, these factors are categorized using Lambert and Loiselle (2007)'s two-construct framework.

*Knowing When To Search.* Information seeking is generally initiated when an individual realizes that they would like to know more information on a topic than they currently do. This discrepancy is thought to drive a motivated information search process (Griffin, Dunwoody, and Neuwirth, 1999; Afifi & Weiner, 2004). The force that emerges

from information discrepancy is not considered a skill in itself but rather a product or outcome from an individual having the skill of recognizing when they need more information about a topic in an effort to make a decision. Individuals would need to be able to recognize when a distance exists between what they know and what they would like to know. The proposition for including this as a skill important for finding health information is supported by the research in the area of information literacy, which suggests that individuals should have the ability to “determine the nature and extent of information needed” (Nail-Chiwetalu, & Ratner, 2006, p.158).

*Credibility Assessments.* In addition to knowing when to search for information, individuals may or may not also have experience finding information within specific types of media. Griffin, Dunwoody, and Neuwirth (1999) frame this concept as the beliefs an individual has about a specific platform (e.g., will a platform, such as a newspaper, provide information); however, these “beliefs” could be framed as the ability to evaluate a source or piece of information on a continuum of credibility. In addition to assessing a source’s credibility, an individual may also have the skills for accessing the media platform in the first place. For example, an individual may have the skills to go on the Internet and browse for health information, but their skills for finding someone to ask a health question could be lacking.

*Reading Ability.* Given the birth of health literacy from general literacy (Berkman et al., 2010), this concept is often thought of and measured as one’s ability to read health information materials. For example, the TOFHLA (and shorter S-TOFHLA) captures an individual’s “reading comprehension” within a health information context (Parker et al.,

1995). Similarly, a central focus of the NAAL was to determine prose and document literacy or, how well an individual could find and use information in continuous and non-continuous texts, respectively. NAAL research utilized a health information, rather than general context, where participants completed prose and document literacy items in clinical, prevention, and navigation of health system contexts (Kutner et al., 2006). It may be that looking for information in a health context is different from a general, or non-health context; however, this is a lack of research in this area. As such, reading ability, specifically within a health information context, should be included as a health information seeking skill.

*Finding Numerical Information.* Similar to the reading ability concept described above, NAAL and the TOFHLA also include a quantitative literacy component, where individuals are asked to find and use numerical rather than word information (Kutner et al., 2006; Parker et al., 1995). Other health literacy measures such as the NVS also rely on having individuals scan, identify, and use numerical information in order to solve problems (Weiss et al., 2005). This concept is often measured separately from an individual's ability to find word-based information. This is critical as individuals often exhibit greater difficulty with these quantitative-oriented tasks than reading tasks focused on words (Estrada et al., 2004; Reyna & Brainerd, 2007) – more research that addresses quantitative information is needed (Woloshin et al., 2001).

*Interpersonal Seeking.* Another skill potentially needed for finding health information is the ability to communicate with others about health topics. These skills might be needed not only to formulate questions in an effort to “find” health information

from others, but could also include the ability to listen to health information and extract relevant details. A review by Williams and colleagues (2002) highlights several specific abilities that may be needed for an individual to find health information within interpersonal conversations. These include, but are not limited to having an understanding of health-related vocabulary and being able to communicate about a health issue, especially to a physician.

Following the framework from Lambert and Losielle (2007, p.1013) and informed by the existing health information seeking frameworks and health literacy research, the skills listed in the table below may come into play when finding health information. This list is seen as a “rough draft” to the themes that could be included in the interview guide for work with patients and health professionals; however, ultimately these groups will play the biggest role in forming the items for a health information finding instrument.

<b>Information Type</b>	<b>Information Amount</b>	<b>Method</b>
Credibility Assessments Finding Numerical Information	Knowing When to Search	Reading Ability Interpersonal Seeking

Table 2.4.2: Health Information Seeking Themes Through Literature Review

Research has only begun to untangle this first facet of health literacy from others. In one study, low health literate individuals spent more time looking at information on the NVS nutrition label that was not relevant to answering the NVS questions than individuals who had adequate health literacy (Mackert et al., 2013). These findings suggest that patients with low health literacy might be able to understand health information just fine, but they are currently spending more time looking at information

that is not relevant to them – they may be experiencing difficulty in pulling out the information they need when they are presented with more information than needed.

Individuals with low health literacy may be more likely to engage in a highly limited information search – often preferring to go to a healthcare provider or cancer organization first for information about cancer (talking to someone directly and avoiding additional information search), in comparison to looking at cancer-related information online first (feeling out the information on their own), which was found to be the preferred source of initial information of those with adequate health literacy using national HINTS data (Champlin, Mackert, & Dudo, in progress). Looking for information in a health context can have critical implications for patients and the source from which patients receive information from first may shape their future information seeking efforts and their understanding of the information itself.

It is clear that finding health information, the first facet of health literacy, represents a unique goal that may be reached through specific skills. Future intervention work could aim to address this facet of health literacy by creating more accessible health information materials. Research in this area suggests that design quality plays a role in whether individuals attend to health materials and how they feel about them, where a mid-level of design quality (one that includes some design principles and elements, but does not throw a high level of text and graphics on the page) actually acquires the greatest attention and most positive evaluations from viewers (Champlin et al., in press). In addition, individuals are more likely to recall health information when it is formatted as a combination of pictures and text information (Houts et al., 2006). Although it is



known that the layout of health information is a critical component for seeking and finding health information, it is not often included as a focus of health promotion research (Aakhus, 2007; Aakhus, & Jackson, 2005; Joffe, 2008).

A study that aims to determine the skills needed for finding health information follows in the next section. This represents an initial step in testing the model of health literacy described in Appendix A. Creating an instrument that captures the skills needed for finding health information could lead to intervention work in this area. With an effective measurement instrument, we can capture changes in one's skills for finding health information over time, which may result in overall improved health. This study would be used as a model for creating similar instruments for the other facets of health literacy. Ultimately, with four instruments that capture the facets of health literacy, we will have a better understanding of the variables that drive this concept, where patients struggle the most, and which facets share the greatest link with various health outcomes.

### **3.0 METHODS**

Without an accepted definition of health literacy or supporting framework and measure, understanding this concept and observing changes over time is difficult. As such, interventions that improve health literacy skills are lacking. In an effort to better explicate health literacy and create a measure that reflects the broad collection of skills comprising this concept, the present study focused on one facet of health literacy (Appendix A); having the skills to find health information. Skills for the other facets of health literacy (understanding, using, and communicating about health information) will be explored in subsequent studies that will be built using this study as a model for study design.

The present study employed a “validity-driven” (Osborne et al., 2013, p14) method of instrument development in which interviews with key informants provide the basis for the language and concepts that comprise a quantitative instrument. Content, criterion, and construct validity are worth emphasizing in instrument development so that the resulting tool gets as close as possible to capturing the variable of interest rather than something else (DeVellis, 2003). These validity efforts can be increased through the incorporation of patient and provider voices rather than relying on literature review and the perspective of the researchers alone (Jordan, Buchbinder, & Osborne, 2010). In addition, convergent and divergent validity can be addressed using this approach by testing many items and evaluating which of these items reflects specific factors (Keith, 2006). A focus on increasing validity in instrument development is particularly important

in the study of health literacy, a concept that includes interactions across patients, providers, family members, the media, and others. Because health literacy is relevant to a variety of individuals, it is important that these perspectives are included to ensure that the instrument that is created does not give preference in any given direction (e.g., a healthcare provider and a patient might have a very different opinion about the skills the patient needs to find health information.).

As such, in this approach to instrument development, items are generated using information provided by these individuals. Themes are extracted through qualitative interviews, which are then used to build instrument items. The performance of instrument items is evaluated using a relevant sample, which includes the application of confirmatory factor analysis. Instrument items that do not perform well are evaluated and potentially removed from the instrument and the remaining items are again evaluated using a relevant sample. This process has been used in previous work (Buchbinder et al., 2011), and specifically in health literacy instrument development research (Jordan et al., 2013; Osborne et al., 2013); however, it has not yet been applied to understand specific health literacy facets.

Although there is a substantial body of literature investigating the process and reasons why individuals seek health information, there is little research on the skills needed to successfully find health information. As such, the central purpose of this study was exploratory in nature. Given the lack of existing research in this area, the present study consists of two phases: Phase One, a qualitative study involving interviews with patients and health professionals to determine, from their perspective, the skills that are

needed from individual to find health information, and Phase Two, an exploratory quantitative study that aims to put themes extracted from Phase One into an initial measurement tool. As such, the present study has one key research question that will be answered using these methodologies:

RQ1: What skills does an individual need to find health information?

### **3.1 PHASE ONE: INTERVIEWS WITH PATIENTS AND HEALTH PROFESSIONALS**

#### **3.1.1 Participants**

Patients of varying levels of health literacy and health professionals were purposefully recruited for the qualitative phase of the present study. All participants (N=40) read and spoke English fluently. Given the potential for limited literacy of some participants, a researcher described the study to the participants and gave the participants the opportunity to read the study's consent form and ask any questions. All participants provided oral consent to the study.

Patients were recruited through two distinct efforts. First, 17 students at a general equivalency diploma (GED) attainment center were recruited by asking a teacher at the center to make an announcement in the classes. These students were currently working toward their GED or taking life skills courses such as learning how to use a computer and the Internet. Participants indicated their interest in the study on a sign-up sheet posted in one of the classrooms. Thirteen administrative staff members at a large, southern university were recruited for participation in the present study. These participants were recruited through an announcement posted through an electronic events list, which is emailed to all campus faculty, staff, and employees on a daily basis. Interested

participants were asked to email the research assistant to set up a study appointment. All patient participation took place in person and each participant received a \$20 gift card to a local grocery retailer.

The qualitative phase of the present study also included ten health professional participants. These participants were recruited using a snowball sampling technique where contacts from the researchers' previous studies were used to recruit health professional participants through email and phone calls. The health professionals in this study included a variety of occupations such as a nursing professor, community health worker, clinical nurse specialist, health promotion director, maternal and child health program specialist, health education volunteer and supervisor, health literacy educator, and chronic disease program managers. Participation from health professionals took place either over the phone or in-person. These participants were not compensated but showed enthusiasm for the study.

### **3.1.2 Measures**

An open-ended interview guide was developed for the qualitative phase of the current study (Appendix B). The present study was based out of a Grounded Theory approach, which allows for the interview guide to evolve over time in an effort to point to the specific skills and mechanisms for finding health information. As suggested by Corbin and Strauss (2008), the initial interview guide is structured to incorporate sensitizing questions, which are meant to shed light on the overall process of finding health information. Sensitizing concepts create "directions in which to look" (Blumer, 1954). This strategy to interview development has been used in previous research

(Donovan-Kicken, Tollison, & Goins, 2011). As informants give information over time, the researchers know more about how this topic unfolds and can then ask more detailed and theoretical questions, which address nuances of whether finding health information differs across media platforms or health topics. As such, the initial interview guide is seen as semi-structured and evolved over time (evolution is documented in Appendix B).

The interview guide began with an icebreaker question, which asked participants to describe a time they looked for any kind of information: What did they do to get the information they needed? Did they encounter any problems and if so, what did they do to solve the problems? After this initial question, the interview guide moved into the central idea of health information seeking, which was broken down into several interview questions. The use of several questions was an effort to encourage participants to talk about their experiences looking for health information and under what conditions they performed these activities, which might shed light on other skills needed to find health information that were not immediately brought to mind when participants were asked about skills directly. Participants were also asked about their thoughts on whether the skills needed to find health information were different from skills they would need to find any kind of information (e.g. a bus schedule). The interview guide was intentionally designed to adapt easily and include emerging themes as needed.

### **3.1.3 Procedures**

One-on-one interviews were conducted with patients and health professionals. Each interview was recorded using a free, downloadable program, *Audacity*, through a MacBook Pro laptop computer. All patient interviews took place in-person and were

conducted in a quiet room. Health professional interviews either took place in-person in a quiet room or were conducted over the phone with the research assistant in a quiet room. Interview appointments, including reading of the consent form and answering of any questions, were scheduled for one-hour intervals.

At the end of each patient interview, all participants were asked to provide demographic information including their gender, race/ethnicity, age, and occupation. Additionally, all patient participants were asked to complete a brief health literacy screening measure, the Newest Vital Sign (Weiss et al., 2005). This was performed only at the end of patient interviews so that it was known whether the interviewee provided a perspective from an either adequate or less than adequate health literate individual (so potential differences between the two can be determined), but did not open the interview in case this generated anxiety among some participants. The NVS is a valid and reliable measure of health literacy and commonly used in health literacy research (e.g., Mackert et al., 2013). A detailed description of this health literacy measure is included in the Literature Review.

### **3.2 PHASE TWO: QUANTITATIVE SURVEY ITEMS**

The second phase of the present study aimed to create a measurement tool that captured an individual's skills for finding health information. The skills included in this tool were informed by the findings from the first phase of the study, which asked patients and health professionals what skills were needed to successfully find information about health. The purpose of creating a measurement tool for this facet of health literacy was to take an initial step towards creating a comprehensive measure of health literacy skills.

### **3.2.1 Participants**

Participants in the quantitative phase of the present study were 335 current members of Research Now, a market research consumer panel. Research Now hosts research panels across the globe and has 6.5 million active panel participants. Panel participants receive an email with the study link when they qualify to complete a study.

Research Now maintains the privacy and confidentiality of their panel participants through the use of secured and encrypted servers and Research Now rotates their participants using a process of participant randomization, to improve the likelihood that the same participants are not taking more surveys than others. Research Now participants are given a participant ID number and their data is never matched with any identifying information.

The approximate length of the survey was 30 minutes. Because of the association between racial/ethnic minority status and a greater likelihood of having less than adequate health literacy, Hispanic and Black adults were oversampled in the present study (Nielsen-Bohlman et al., 2004; Paasche-Orlow & Wolf, 2007). Given these requirements for the study (length and oversampling), Research Now estimated that each participant would be compensated roughly \$8.75 for their participation in this phase of the present study.

### **3.2.2 Measures**

Items for the present study were developed using language from Phase One interviews. For example, patient participants in Phase One told many stories about looking for health information online. This shed light on the items that should be



included for the Finding Health Information Online factor, such as the feeling of being “bombarded” with information or the ability to use search engine modifiers such as quotes and dashes to narrow an online search. Using language from patient participants increases content validity for these survey items. In an effort to further supplement the content validity of these items, six additional health information content specialists reviewed the items and provided suggestions for increasing content validity.

Based on the limited previous research available on this topic and the findings from the present study’s first phase, a total of seven skills were identified for inclusion in the initial version of the measurement tool. Descriptions for the first five skills are included in the Literature Review. These five skills were supported through patient and health professional qualitative data from Phase One of the present study. Two additional skills were uncovered through Phase One interviews: Finding health information online through Internet searches and the concept of spatial navigation. The seven skills are defined and supported by participant quotes in the Results section for Phase One. For each of the seven skills, participants completed self-report items created from quotes and language that emerged in the Phase One interviews (Appendix C). Additionally, participants in this phase completed demographic items and a variable for the purpose of verifying for discriminant validity, as described below.

*Knowing When to Search.* Existing information seeking models such as those discussed in the Literature Review emphasize that this behavior is motivated by a discrepancy between the amount of information an individual currently has and the amount of information they would like to have (Griffin, Dunwoody, and Neuwirth, 1999;

Afifi & Weiner, 2004), rather than passively absorbing content. As such, it may be that individuals need to have the skill of recognizing when it is time to look for health-related information instead of acting (or not acting) on a health concern without having the relevant information. In the present study, a self-report scale was loosely adapted from the Theory of Motivated Information Management (TMIM) (Afifi & Weiner), paired with findings from Phase One qualitative interviews.

Participants were asked the level to which they agreed or disagreed (1=Strongly Disagree, 7=Strongly Agree) to a set of seven statements regarding their skill for knowing when it would be time to look for health information. Three of the statements were reverse coded. In Phase One interviews it became clear that having an understanding of one's own health history might motivate health information seeking, where a "new" health problem might be more likely to motivate seeking versus a health problem for which someone had had experience and may not feel that more information on the topic was needed. Thus, having an understanding of one's own health history or "health context" was also relevant. Items were created that reflected these concepts (e.g., "I know when to look for health information; When I read information about a health topic, I am able to tell whether or not the information applies to me." )

*Credibility Assessments.* Previous research by Metzger (2007) and Eastin (2001) suggests that there are a number of content elements that might influence an individual's assessment of information credibility including the source (who is the information coming from?) and the content (is the information accurate?). In the present study, participants were provided with an adapted version of Metzger's list of frequent

information verification behaviors (e.g., Consider the author's goals/objectives for posting the information; Check to see if the information is complete/comprehensive) and asked to report the frequency in which they engaged in each behavior (1=Never, 5=All of the Time). The survey included ten behaviors, five of which were reverse coded.

*Reading Ability.* The NAAL suggests that there are three key modes of content: prose, document, and quantitative material (Kutner et al., 2006; Rudd, 2007). For the concept of reading ability, self-report items were generated for prose and document skills. In the present study, participants were asked to rate the "level of difficulty you would have with finding [TEXT-based] information in each of the following printed materials," which was followed by a list of different modes in which health content could be presented, including six types of prose (e.g., "a magazine article") and six types of documents (e.g., "an over-the-counter medication label). A 7-point Likert scale was utilized where a 1 indicated that the participant could not find text-based information in the specified context and a 7 indicated that the participant was always capable of finding information in the specified context.

*Finding Numerical Information.* As indicated above, the NAAL outlines three key modes of health-oriented content (Kutner et al., 2006). In addition to prose and document reading abilities, which focus on finding text information, individuals also look for quantitative information. For example, an individual may search through a research article to find the rate of deaths related to diabetes in the U.S. each year. To capture this skill, participants were asked a question similar to that for reading ability and were to "rate the level of difficulty you would have with finding health information in these

printed materials if you were looking for NUMBERS-based information, rather than text-based information.” Participants were again provided with the same list of content modes and the same 7-point Likert ability scale that were utilized for the reading ability skill.

*Interpersonal Seeking.* In addition to having the skills to find health information in printed materials such as books, pamphlets, or websites, participants in Phase One also outlined the need to have communication and listening skills to be able to “find” health information by consulting other people, mostly with medical professionals. It was determined that the skills one would use to find health information from the aforementioned individuals would not necessarily be different across people; an individual would use the same skills regardless of the type of person providing that information. This is different from the amount of efficacy one might have for talking about health topics with each of these individuals, which might differ across person type, as outlined by TMIM (Afifi & Weiner, 2004). As such, a list of items was created which were thought to reflect the types of skills one might need to successfully find health information in this way. Using the same 7-point Likert scale as the reading ability and finding numerical information skill domains, participants indicated the amount of difficulty they would have with several communication exchanges (e.g., Asking questions about a health topic; Following along in the conversation.”) if they were “having a conversation with another person about health.”

*Finding Health Information Online.* Participants in Phase One of the present study described finding health information online as a distinct set of skills that might occur in conjunction with reading ability and finding numerical health information. It may be that

using the Internet facilitates some health information seeking but also creates a number of barriers to health information access if one does not have the skills to perform quality online searches. Self-report items for this skill domain were adapted from eHEALS, a measure of health literacy in an online context, which aims to “measure consumers’ combined knowledge, comfort, and perceived skills at finding, evaluating, and applying electronic health information to health problems” (Norman & Skinner, 2006, p.27). Although labeled as a health literacy scale, this eight-item measure more likely reflects one’s comfort with or efficacy for using the Internet than a skill set for performing this behavior. Moreover, it is unclear whether individuals would respond to these items differently for using the Internet to find *any* information, rather than health-specific information. As such, the self-report items used in the current study were adapted to capture a skill set for finding health information in a health context. Participants indicated the level to which they agreed (1=Strongly Disagree, 7=Strongly Agree) with eight statements (e.g., I know how to find helpful health resources on the Internet; I can use online search strategies such as quotes and dashes to narrow my searches for health information.”) Four of these items were reverse coded.

*Spatial Navigation.* The Santa Barbara Sense of Direction Scale (SBSOD) was used in the present study to capture participants’ self-reported ability to find and travel to places in their environment. In previous research, this measure exhibited good internal consistency and test-retest reliability (Hegarty et al., 2002). Due to the length of the survey, this scale was adapted to incorporate five of the items from the original 15-item measure. Items were selected based on their reported factor loadings by Hegarty et al.,

where the items used in the present study loaded onto the same factor, thus suggesting that the items shared strong correlations. Participants indicated the level with which they agreed to these five statements (e.g. “I am very good at giving directions;” “ My sense of direction is very good.”), where two of the statements were reverse coded (1=Strongly Disagree, 7=Strongly Agree).

*Sensation Seeking.* The purpose of the present study is to determine the skills needed to find health information. However, an individual may have the skills to find health information but choose not to utilize those skills. This behavior could be related to health-related risk taking. Examples of risky health behavior include engaging in unprotected sex, binge drinking, not wearing a seat belt, and other behaviors that put an individual at substantial risk for mortality. Although evidence in this area is limited, some suggests that risky behaviors such as those mentioned above may share a stronger association with the concept of sensation seeking, or, having the desire to try many new experiences (Zuckerman, 1979), than lacking the ability to control one’s behavior (also known as impulsivity) (Galvan et al., 2007). As such, a brief measure of sensation seeking (Steinberg et al., 2008) was included in the present study. This measure has been used in previous research (Steinberg et. al., 2008) and included six statements for which participants indicated whether or not the statement described them using a 4-point Likert scale (1=Doesn’t Describe Me Well, 4=Describes Me Well). Sensation seeking is viewed as a personality trait or characteristic: a person’s tendency to perform in a certain way. While this concept might be related to having skills for finding health information, analysis in the present study should suggest that these concepts are, in fact, uncorrelated

with the skills measured in the study that are thought to reflect health information seeking skills.

### **3.2.3 Procedures**

After clicking on the study link to the Research Now research study availability page, participants were presented with the consent form for the study. Participants indicated whether they agreed to participate in the study after reading this consent page. If they indicated that they did not agree to participate in the study, the study terminated at that point. For those participants interested in being included in the study, they were advanced to an instructional screen, which let participants know that the information in the survey was not to be used for medical diagnoses of themselves or others. After reading these instructions, participants completed the self-report items designed to capture the seven themes identified from Phase One. The self-report items were randomized to control for the order in which the items were completed. After completing all self-report items, participants completed a series of demographic questions.

## **4.0 RESULTS**

The purpose of the present study was twofold: 1.) to determine, using qualitative interviews with patients and health professionals, what skills are needed for an individual to successfully find health information and 2.) to then create a quantitative measure that captures these skills. Because the quantitative measurement tool was built using ideas and quotes from the Phase One qualitative interviews, these results will be presented first.

### **4.1 PHASE ONE RESULTS**

#### **4.1.1 Phase One Participant Characteristics**

Forty participants were included in this phase of the current study. These participants were purposefully recruited to reflect patients of adequate (university staff, n=13) and less than adequate (GED attainment center, n=17) health literacy and health professionals (n=10). Of the 17 participants recruited at the GED attainment center, 11 were female. This sample was fairly diverse including 7 African American, 5 Hispanic, 2 Mixed-Race, 2 “Other,” and 1 White participants. The average age of this sample was 41.12 years. The NVS score of this sample ranged from 0 to 4, with an average score of 1.65 (SD=1.58), indicating a “high likelihood of limited literacy” (Weiss et al., 2005). Although this sample of participants was purposefully recruited as individuals who would have a high likelihood of having low health literacy, three participants at this center scored a 4 on the NVS measure, which indicates adequate literacy. Because the focus of the present study was to obtain insight from patients with low and adequate health literacy, participants at the GED attainment center having adequate health literacy were



not included in the present study. Interviews with this sample were conducted first and ranged from 25 to 45 minutes in length.

Of the 13 university staff participants, 7 were female. This sample included 7 White, 2 Hispanic, 2 “Other,” 1 Mixed-Race, and 1 Asian participants. The average age of this sample was 33.69 years. NVS scores for this sample ranged from 4 to 6, indicating that all university staff participants exhibited adequate health literacy, and the average NVS score for this sample was 5.62 (SD=0.77). Interviews with this sample were conducted second and ranged from 31 to 51 minutes in length.

Ten health professionals were included in Phase One. Nine of these professionals were female. This sample included 7 White and 3 Hispanic professionals. The average age of this sample was 42.75 years; however, age was not collected for two of these professionals. Health literacy score was not collected for health professional participants. Testing the health literacy of health professionals may have had a negative impact on the rapport between the researcher and the health professional, where professionals may have felt that their expertise or training was being assessed. The purpose of interviewing the health professionals was to explore ideas about the skills patients use for finding health information and not to establish whether or not the professionals were indeed health literate. Interviews with this sample were collected last and ranged from 19 to 56 minutes in length.

#### **4.1.2 Phase One Analyses**

Phase One data were analyzed using two methods. First, after the completion of each day of qualitative interview data collection, the researcher listened to each interview

and took notes on emerging codes and themes found in the data collected on that day. After the first day of data collection at a new site, these notes were more substantial than towards the end of data collection at a given site as consistent themes and codes converged as more data was collected at each site. These notes were used to transform the interview guide over time so that the interview questions became more specific to the research question of interest and to elucidate key codes and themes. The interview guide was continuously updated as data was collected with GED attainment center patients (Appendix B). The version of the survey that resulted was then used at the start of data collection with the university staff. Few changes were made to the interview guide while collecting data with the staff given the general consistency in themes and codes throughout a majority of these interviews. For the health professional interviews, the initial version of the interview guide (which included some slightly different interview questions than the interview guide written for patients, see Appendix B) was combined with the final version of the patient interview guide to create the interview guide for health professionals. Themes and codes within the health professionals sample showed great consistency even in just the first few participant interviews in this sample. As such, only minor adjustments were made to the health professionals interview guide over time.

A second phase of analysis took place after all of the qualitative interviews were conducted. This second phase included a number of steps. First, the researcher listened to each of the 40 interviews several times while taking a series of notes. Common codes were extracted from these notes and compiled into a series of diagrams in an effort to place the codes in a sequence or health information seeking narrative. The codes from

each of the three samples were then collapsed into major themes. These themes are described using examples from the data below.

#### **4.1.3 Phase One Themes**

The qualitative interviews included in this study produced seven key themes regarding the skills that participants felt would be needed for an individual to successfully find health information. One difficulty of having participants discuss “skills” for finding health information was that participants often discussed personality traits (e.g., a person’s willingness to perform steps of the information seeking process itself; a person who will engage in a trial and error process when looking for information). Only information that was deemed “skills-oriented,” or, something for which a person might be likely to change through the process of learning new information (and not a more engrained personality trait), was considered for codes and themes in the present study.

Generally, patient participants, regardless of health literacy level, thought that it was easy to find health information. Even for those who could not use a computer, it seemed that it was not that hard to “just ask someone” about a health topic. As such, participants generated few ideas for the skills that might be needed to find health information that were not already suggested through previous research. The two themes specifically generated from interviews with patients were the importance of being able to use a computer and having Internet/search engine-related skills and the skill of being able to navigate directions and environmental space in order to get to health-related facilities. The Internet and computer use skill was more commonly discussed among the university staff (those having adequate health literacy). In contrast, many patient participants at the

GED attainment center (those having less than adequate health literacy), rather than going online for health information, often described the need to travel to a health center to get health information they needed. These participants told their stories of having to find an appropriate health center by using navigational skills – including getting directions, remembering street names and relative locations, and being able to navigate a bus schedule or walking routes. This was a central difference found in Phase One interviews between those of adequate and less than adequate health literacy.

Additionally, it should be noted that, although patient participants mostly agreed that finding health information was not a difficult activity, the mode through which this information was received clearly differed. For example, less than adequate health literacy participants asked “anyone” for health information and participants while the health literate patients consulted more knowledgeable sources, such as a doctor.

Overall, interviews with health professionals corroborated themes found among patient participants. However, these participants often communicated concern about where patients of different levels of health literacy got their information and how much of that information was evaluated, understood, or trusted. These health professionals tended to describe themselves as a “go-to” source for health information for their friends and family members. Many professionals wished that everyone (patients of all levels of health literacy) had access to a person in their community who could help answer health-related questions. However, health professionals also noted that they felt that many patients who needed the greatest help with their health (and finding health information) often were not the ones looking or putting effort towards these activities.

The first five themes outlined – Knowing When to Search, Credibility Assessments, Reading Ability, Finding Numerical Information, and Interpersonal Seeking – are those that were identified through previous research and existing literature as potential skills an individual would need to successfully find health information. Interviews with participants in Phase One of the current study clearly supplemented these themes while also adding some specifications or codes not yet considered in the literature review. Then, the final two themes – Finding Health Information Online and Spatial Navigation – that were elicited entirely through Phase One interviews will be described. Participant quotes from Phase One interviews are included to give examples of the themes. Note that ellipses within quotes indicate a skip to a later section of the same participant’s interview.

*Knowing When to Search.* Information seeking models propose that this behavior occurs when an individual realizes that they do not have as much information about a topic as they would like to have (Griffin, Dunwoody, and Neuwirth, 1999; Afifi & Weiner, 2004). Participants in Phase One of the present study elaborated this in several ways. First, many participants indicated that they would search for health information when they felt they needed that information. Most often, participants identified that health information was needed when someone (either the participant themselves or a close family member/friend) was sick. However, even so, health professionals noted that many people may recognize that they have a health problem and avoid seeking health information because they are afraid or in denial of their change in health status, so they may actively avoid health information.

Additionally, participants often described that an individual should have an understanding of the health information that could be relevant to them. This idea includes any previous diagnoses and health history or experience. For example, if an individual had a bad headache, they would not look for information about headaches in general but may be able to place, given their health context, why they have a headache. Is it likely that they are dehydrated? Do they tend to get frequent migraines? Given these codes, an overarching skill domain illustrated by participants in phase one was that of “knowing when to search” or, having the skills acknowledge not only when but also what information is needed. This skill is illustrated by participants below.

A less than adequate health literacy participant at the GED attainment center looked for health information for her baby, who was crying after using the bathroom. The participant tried to look for health information online but, because she did not yet have a health context for her baby, it was difficult for her to find information about her baby’s health problem online:

Um...I just put [into a Google search] like...you know...baby you know, crying when using the restroom. Like, what could cause it. And it just said...umm stuff like that, stuff like, oh, maybe the baby needed to take a bath. It was just like...you know, stuff that wasn’t close to what was happening with her.

(Patient #3, Female, 25 years old, Hispanic, Low health literacy)

Another participant with less than adequate health literacy describes how someone might know when its time to look for health information, which emphasizes the presentation of new symptoms:

Yeah, when your health issues go down – 30s you used to do when you were a younger person, you can’t do no more, you find it difficult or tiring

or you're out of breath. When normal, normal society, just do it. Walkin up a hill, if you're winded. You need to look into your health issue. Your lungs, see what's goin on with your lungs. See what's goin on with your blood system. You know what I'm sayin. See if you've got too much, uh cholesterol in your system. You know what I'm sayin. If you're always tired, see what's goin on, with your body, because your body is the one that gets you goin. Because if it doesn't go, you don't go.

(Patient #6, Male, 59 years old, African American, Low health literacy)

This adequate health literacy participant describes an example of a time he looked for health information in response to a recently emerged health concern. This example also outlines how an individual might know what kinds of health information would be most relevant to them:

[Have you searched for health information in the past?] Not too often. Cuz I mean, for me personally, my belief is there seems to be a lot of anecdotal or maybe misinformation online. Like, if I really have a problem, for me personally, I will just call my doctor. So, I would say, not too often but, uh, I guess the last, uh, time that I just looked something up just to see what it could be was um, this little cyst here. So I, you know, just typed in like, 'bump on wrist' or something into Google and um, you know, some things came up.

(Patient #20, Male, 32 Years Old, Asian, Adequate health literacy)

Many participants indicated that they looked for health information mostly when they (or someone they know) were sick. However, information discrepancy was sometimes illustrated in a more positive way. The participant below discusses how his friends mostly looked for information on health topics that they wanted to know more about, but were already healthy individuals.

Like, most of the people that I come in contact with or that I know that would, you know, be looking for this information are, like they're not trying to necessarily, like they wanna, I'm thinking, like, they didn't go to a doctor and were told they were sick and need to change something. So I can't necessarily, I don't know what it would be like for, someone who is obese and went to the doctor and they're like, you have to fix this, and

they're trying to do that. Like, I think that most of the people I know start on the other spectrum right, like they're kind of okay, but they want to be better. Right? And they've decided, you know, their diet's okay, but they want it to be even better. Or they're, you know, training for a marathon and they want to match up their diet that's going to optimize that.  
(Patient #19, Male, 32 years old, White, Adequate health literacy)

Even still, other participants suggested that a big health change or emergency might equip someone with both the need and then the ability (after looking as a result of the immediate need for information) to look for health information.

Necessity is you know, the mother of tenacity. If you're put in a situation where you need it [health information]. I mean, although, some people don't [look for health information]. I don't know what it takes to, maybe it takes a bad experience. Because I can honestly say that if my back surgery had gone perfectly okay, if my mother's doctors had been better, I just would never, I would have left the entire scope of medical information to experts. I would have just said, this is something I don't need to know because I can pay somebody.  
(Patient #21, Male, 40 years old, White, Adequate health literacy)

Similar to the quote from the adequate health literacy participant above, a health professional similarly suggested that experience with health information seeking may result in individuals knowing when they should look for health information and the kind of information they might need.

For other folks, it's based on what their experience has been. You know, what have they tried, have they tried to call and it doesn't work? Have they tried to walk in and they get the attention they need? Or the people that they interact with, their family members, parents, what they've seen other people do when they're sick? But yeah, I think familiarity with the healthcare system makes it a lot easier.  
(Health Professional #5, Female, 33 years old, Hispanic)

But I think the more fundamental thing is that you need to know what you need to know. In order to find it. And, if you don't know what the condition is or how it fits into the larger aspect of health, it is really hard to go out and research on your own.



(Health Professional #7, Female, 72 years old, White)

Health professionals were also quick to note that many patients avoid health information seeking, perhaps because the patient does not want to know about a health topic because they feel it could have negative outcomes for them. Moreover, it should be noted that some patients may not look for health information because they do not experience the information discrepancy between what they want to know and what they already know about a given health topic.

With some of the clients that I work with, they really don't want to know, they feel it's better to not know, instead of knowing and not being able to do anything about it...I don't think people really listen and read pamphlets or booklets or really any literature that's given from their doctor.

(Health Professional #3, Female, 34 years old, Hispanic)

Another health professional noted that, "Denial is huge too. If I [the patient] don't acknowledge this, maybe it'll go away."

*Credibility Assessments.* As mentioned above, participants generally thought that the skills needed to get health information were not all that complex; noting that one could ask anyone about a health topic and they might be able to give you information. However, participants did propose that that being able to get factual or accurate health information could be difficult. This theme was present across participants but was more common among patients with adequate health literacy and health professionals. These participants discussed some specifics that they used to evaluate health information from different sources. These strategies were often difficult for participants to put into words and were sometimes described as a gut feeling or inclination they had about the content and its source. One key question that arose was about whether the information was given

in an effort to sell a product, which was often seen as less credible than information not aimed at selling anything. Making these evaluations were often described as more common and perhaps of greater importance when looking for health information online, where determining the source of the content was frequently more difficult.

Interestingly (and somewhat in contrast to the findings above), almost all of the participants included in Phase One described some skepticism towards health information from any venue (including doctors and pharmacists). This was often paired with the expectation that health professionals should have a clear answer to every health question and that any uncertainty was seen as highly disappointing to patients. Quotes from patients and health providers about the skills they see as necessary to evaluating source, content, and channel credibility are outlined below.

First, a less than adequate health literacy patient exhibits her surprise that the doctors she was working with on a health issue were not able to give her the amount of information she desired. This lack of a met expectation results in her skepticism towards information provided by doctors. As a result, this participant took to social media to crowd source suggestions for a serious health concern.

I'm like...really? Y'all don't know anything about this? It wasn't...a lot of doctors don't know about that – and, um, I educated him on it – and he kinda educated me on some of it. But, they really not aware of that. A lot of women don't even know that they can get that. You know?  
(Patient #9, Female, 28 years old, Native American, Low health literacy).

The three less than adequate health literacy patients below describe how it's challenging to determine, among many health information sources, which provides the most accurate

information. These participants outline the strategies she uses to determine whether the information is accurate.

That's the difficult part. But mostly, like when you see when most people are saying, do this, and one thing is saying, no, do this – you wanna go with the one where a lot of people are sayin don't do this. Yeah, you just got to weigh your options, weigh your differences. Sometimes you can like, right away know it's a scam. But you just gotta be really careful. But like, a lot of them – if you don't see their brand – their little symbol? Then you automatically know its spam.

(Patient #11, Female, 32 years old, Hispanic, Low health literacy)

To me they put it out there [information on the Internet] – hopin people would read it – you know, and everything that you read necessarily is not right – or it could be bogus, but um, to really keep people informed. To give people information they can use to take to the next step, you know, so. Sometimes it can be tricky because sometimes you have to be on trusty sites. And who knows what's a trusty site?

(Patient #16, Female, 51 years old, African American, Low health literacy)

One less than adequate health literacy participant also went on to note, “I just clicked on any one that looks right – seems right – and I just clicked on that.” Adequate health literacy patients also described skepticism toward health professionals and the information they provide. This could be paired with the skills these patients use to screen health information from other sources for credibility, such as participant 19 who compares information across forum posts and participant 11 above.

Sometimes it'll be like a forum will pop up. And. You know, with the way I treat forums online, it's kind of like, I'll go to more than one, right...I'll maybe go through like, a bunch of them. And if I already had a feeling about what the problem is, and then like, five forums are all saying the same thing, then I'll be like, okay, everybody is agreeing with what I thought...like, with health information, particularly forums, it's like, I don't ever know, never might be a strong word. But I don't always know, there seems to be a lot of information just out there.

(Patient #19, Male, 38 years old, White, Adequate health literacy)

I guess there's the trust, that if you go onto an established organization's website, um, or something that at least seems official, that's like, the first level. And, if you, if then, the article happens that it was written, if you know was written by an expert, then that would be good. If it has citations um, to actual medical journals or whatever. Wikipedia often does now. That's an indicator of good health information. So, bad health information would be, it's not necessarily bad in the sense of its wrong, per se, but its just not as trustworthy. So, that would be like more anecdotal stuff.  
(Patient #20, Male, 32 years old, Asian, Adequate health literacy)

Health professionals often described patients as likely not evaluating source and content credibility from many health information-providing sources. However, professionals did occasionally admit that even they did not always check every fact in an article or other piece of health information.

I think that, a lot of the time, it's important to read the information with as much of a critical eye as possible. I think too often we as a society have gotten into the habit of saying stuff like, 'studies have shown' [without actually knowing what the study did]...I think it's important that if we're talking about professionals and the way we should be doing something, you have to make sure that when you read something, you determine if, you know, what's being said and think about it from perspectives of historical perspectives or um, the way that we used to do things or the way it was done in the study.  
(Health Professional #2, Male, 33 years old, White)

I don't think the regular user can discern what is reliable or accurate [regarding health information online specifically]. It's like, the regular user doesn't know to not click on some kind of spam that gives them a virus, you know? I'm surprised that people go for that stuff, but they do. For them to be able to tell the difference between what's an accurate or reliable source and not is also challenging.  
(Health Professional #5, Female, 33 years old, Hispanic)

*Reading Ability.* Being able to read through health documents was one of the most common themes across the Phase One interviews. When asked about the skills needed to find health information, having reading skills was also the first skill that came to mind for

most participants. Different aspects of reading were described across interviews, these included being able to scan text, being able to understand health-related words, and take messages away from what was read. What also became clear is that this reading ability within a health context might get easier with more practice; if an individual looked for information on a given health topic, they would likely have a better, more prepared, place to start looking for information on the same topic (if they indeed looked for this information again). Additionally, health professionals described adequate reading level as an important (or maybe the only) component to creating “good” health information content.

Well, knowledge, like, good reading skills, and being able to follow directions really well – and you know, be able to understand, you know, that they get the information, and they read in and kind of go along with it, so, it’s pretty much like, educational skills, it would be...Some people do [have a hard time finding health information] – especially if they don’t mmmm – have the, good reading skills. That makes it hard for them to understand what they’re looking at. Or if they get something to read – it would be hard for them to read and understand because they’re really not comprehending the words. So that would be harmful to their understanding if they don’t have somebody to guide them through stuff or you know, read stuff to them, you know, most people understand when you read stuff to them as opposed to them reading it themselves, because they have a hard time reading. So, you know, you gotta mentor them and help them through stuff.

(Patient #4, Female, 58 years old, African American, Low health literacy)

This less than adequate health literacy participant struggled with reading through a pamphlet on health insurance at first, but as she began to read through the information included, she realized that the information was presented in a specific order. One of the NAAL foci was “document literacy” which emphasized being able to read health information-related documents such as the participant’s health insurance pamphlet.

I guess you just really have to know what you're looking at – cuz they [a pamphlet on health insurance] explain – like I didn't know they were doin my cities. And the first place, was, for you know, kids, and then the second page was like, eye doctor, and I didn't know that. I just thought it was a whole bunch of names on there – and I was like – what am I supposed to do?

(Patient #3, Female, 25 years old, Hispanic, Low health literacy)

Participants discussed reading as a way to get a knowledge base on a health topic over time. Having the ability to read allowed individuals to acquire information they were looking for. The type of information they looked for over time changed based on what they were able to read. This participant had a mother who had recently passed away after having ALS. The participant did not know anything about ALS prior to her diagnosis but, over time, read information about this topic, which ultimately changed the kind of information he looked for over time.

When you actually read about it [ALS] too, just to make people aware of what a horrific, horrific way to die it is. And, you know, that there's actually a lot of people that have the disease and that there's not a lot of money put into research...[Having a bad health experience] made me read things about just like, prescription drugs and things, you know, I mean, if I had followed his [the doctor's] advice I might be dead.

(Patient #21, Male, 40 years old, White, Adequate health literacy)

Having some familiarity with the vocabulary. And also just having that familiarity lets you read certain information that other people may not be able to make sense of...I think you can acquire [the vocabulary] if you start reading the articles that are accessible to you. You'll pick up some terms over time.

(Patient #18, Male, 32 years old, White, Adequate health literacy)

Health professionals echoed patient comments by reiterating that reading health information may become easier as one's experience with this activity increases; specifically, as described above, experience with health-related vocabulary may equip

patients to navigate health materials better over time. Health professionals also point out that basic literacy (the ability to read in general, not just health texts) and reading level must be taken into account in the design of health information. For example, one health professional stated, “[When asked to give advice to patients for finding health information] I would say to, to become as well read on something as possible.” Other health professionals echoed this concept.

First of all, you have to be literate in one language or the other. And probably one of the estimates has been is that we need to assume about a third grade reading level for those patients that are literate in a language.  
(Health Professional #7, Female, 72 years old, White)

I don’t know what the reading level needs to be, but sometimes the information is so full of jargon that you know, are they [patients with low health literacy] really understanding what’s being said? And even folks who are extremely literate you know, have trouble with that.  
(Health Professional #8, Female, 38 years old, White)

*Finding Numerical Information.* A focus of the NAAL was to evaluate, at a population level, the ability of American adults to perform reading and quantitative tasks in a health information context. Participants in Phase One undoubtedly focused on having the ability to read health materials as an important skill for finding health information. Participants did not yield the same certainty for being able to perform similar tasks (i.e., looking through information) for numerically-oriented information such as nutrition or medicine labels, percentages, likelihood ratios, etc; however, they did often describe ways of getting health information that often incorporated finding, understanding, and remembering numbers.

For participants with less than adequate health literacy, the use of phone numbers was a key mode for getting health information, though some of these participants did discuss having to juggle different numbers for doses of the different medications they were taking. This theme was perhaps the least discussed by participants directly yet seemed to play an important role in the stories told by these participants.

Yeah, I would say, on your telephone, there, which is something I use a lot, there's a 211 number, which is a local um, directory of services, uh, and that lists a variety of services. It covers a variety of things. And uh, you know, anywhere from health, to housing, to food, that's a real source. I would recommend that to anybody.

(Patient #5, Male, 58 years old, African American, Low health literacy)

When you take your medicine, you're not supposed to drink alcohol. At least give 30 minutes before you eat. Cuz I get my – I take one at 5 in the morning – that's my high blood pressure. And then my thyroid, I take 30 minutes later – total about an hour's time, about 30 minutes time, I eat. Cuz I have to give the first medicine an hour, so it gets through your system – and the second one, another 30 minutes. But then sometimes I forget to take 'em. And I feel that, the next day. And if I don't take it in the next 2 days, on the 3<sup>rd</sup> day, I feel it. Grouchy.

(Patient #10, Male, 52 years old, Hispanic, Low health literacy)

I might use the phonebook – like the Yellow Pages – practically all I use is the phonebook, then um, um...I use my um, my Gmail to find information too – like for things like jobs, things like that.

(Patient #15, Female, 37 years old, African American, Low health literacy)

Participants having adequate health literacy did discuss finding numerical information more as a step towards more involved quantitative calculations such as being able to understand the use of statistics in creating recommendations for drugs. This theme was not touched on by health professionals, who may have viewed this skill as “too difficult” for those patients with low health literacy.



A prescription is really a chemical median. That's all. It means that they have given this drug and you know to however many thousand people and, on average, this drug does the following. But it also, you know, out of the average, some people just die. Or they shoot blood out of their eyes. And so you have to be aware that this drug doesn't do that, on average, this drug has had the following effect. For some people it won't do that at all. I think that once you realize that and apply that to all medical information, what you're looking for is just the next step of something to try. And it may or may not work for you because we actually all have really individual chemical make-ups and bodies.

(Patient #21, Male, 40 years old, White, Adequate health literacy)

*Interpersonal Seeking.* Participants often identified communication skills as an important component for finding health information. A vast majority of comments made regarding this skill theme were about communicating with health professionals such as doctors. As such, it may be that some feel that this communication exchange truly takes "skill" whereas asking "anyone" might require less of that skill (or even, perhaps, a different skill). Some participants stated that they had no problem asking a doctor any question on their mind, while others noted that asking a doctor a question could be a difficult communication exchange (most commonly, participants did not want to feel intimidated or look dumb in front of a doctor).

The skill of interpersonal seeking is comprised of codes such as being able to formulate a question, understanding what the other person is saying to you, selecting the information in the conversation that is relevant to you, and remembering what happened in the conversation. Another code that fell into this theme was that of skepticism and resistance to ask questions of a health professional, yet other times seeking in-person information was seen as more trusted than information presented in text. A patient with

less than adequate health literacy described a common sentiment about communicating with doctors and other health professionals:

Oh – consult a doctor about information? Uh...uh, that's kind of hard. Cuz you don't know how and what to ask a doctor. And you may be askin him somethin, but he may understand you askin for something else – it's very. You know, there's not like a list [of things you can ask a doctor]...Okay – you're gonna get the information that you need, but then, you're also gonna be intimidated, you don't want to look stupid in front of the doctor or for anybody else. But here [at the GED attainment center], I can be stupid and not feel stupid, and get the information that I need – this place is a good place – it's the best.

(Patient #2, Male, 50 years old, African American, Low health literacy)

A similar comment was made from a participant with adequate health literacy:

When you're sitting in the doctor's office, and you don't have that decade of education that it took to get him there, the whole interaction is really intimidating. And you do, in fact, feel that it's the voice of God.

(Patient #21, Male, 40 years old, White, Adequate health literacy)

Participants with less than adequate health literacy suggested that they improved at communicating with health professionals over time; perhaps as they got older they were less likely to worry about being embarrassed.

Again, in the doctor's office, I mean, that's a place of confidentiality. So we need not be afraid to ask, or explain a uh, definite health problem. I mean, those people are there in confidence, so whatever might be ailing you, I would feel freely, to speak freely about that. You know, so they could get more information from you. You know what they say, a closed mouth. You can't relate to anybody if you don't know what's goin on. I was pretty shy in my younger years, so uh, now that I've come out of that, I know a lot, and I ask a lot of questions. If I want to know something, they said not to be embarrassed by it...Well, I think you know, I found that in my younger years, by not asking questions, learning from all the people to uh, overcome my shyness and feel alright. That you're normal if you ask questions. And even if you don't know the answer, even if you fail, you're still normal, that's just the process in life. I don't know why, why it was like that. But it's just what came out of it and it picked me up a whole lot.

(Patient #5, Male, 58 years old, African American, Low health literacy)

Asking for the help – if you don't – I guess what got easy for me was – like I wouldn't be afraid to ask for help – I wouldn't be afraid to ask questions – no matter how many times the doctors – you got to break it down for me, I'm sorry that is your job - I think I became a stronger person, because at first I would see them get agitated or – she's not understanding – then I would quit. But that's something that would push me – cuz they're my kids – it's something that I need to know about them. So it's what pushed me – you know, you need to explain things.

(Patient #11, Female, 32 years old, Hispanic, Low health literacy)

Some patients explained that talking with someone in person about health information might have greater trust associated with the information than getting that same information from another source.

We just logged onto their [Blue Cross Blue Shield] website and tried to find like a list of covered procedures and how much they cover. And after, I guess after finding that, we just wanted to be extra sure...I just wanted to make sure that they cover this particular type of tooth extraction as well as anesthesia and all that good stuff. So, after I found that, yes, they do cover this I actually wanted to talk to someone at Blue Cross and have them verbally confirm it with me as well because I don't trust insurance companies. So I just wanted to really explain my situation and the procedure to them and make sure that what I'm looking at is what, you know, they are describing basically.

(Patient #20, Male, 32 years old, Asian, Adequate health literacy)

Health professionals offered many takes on patient-provider communication and the ways in which patients might learn the skills needed to ask questions and get answers from these providers.

I think they're [the patients this health professional works with] good at finding the topics because everyone has a cell phone now and their phones are smart phones, so I mean they're really good at finding what they're looking for, because its easier to do that than it is to have that human contact with someone else. Its just easier to deal with it that way.

(Health Professional #3, Female, 34 years old, Hispanic)

If your parents don't tell you, you know, show you, like as a young child, start to tell you, like, go to this adult, or you know, go to the counter and order this food, even something simple like that, knowing to ask, how to communicate even with people in the service industry. I see a lot of young people who, they don't look you in the eye, they feel timid, and I think if people just do things for you, you don't learn even how to communicate that way.

(Health Professional #5, Female, 33 years old, Hispanic)

In the context of the exam room, where there is a power structure, and there is also probably high levels of stress and anxiety so you're getting information in this intense situation and its probably new information so you're not processing it clearly so to say to patients, 'now what questions do you have for me?' is practically an impossible question to answer.

(Health Professional #10, Female, 59 years old, White)

*Finding Health Information Online.* A clear theme elicited from Phase One interviews that was not identified through reading previous literature was the prevalence and reliance on finding health information online. As described above, this theme was more common in patients with adequate health literacy, yet many of the participants with less than adequate health literacy also reported using the Internet to find health information, or the desire to if they did not yet have computer skills. For those without computer skills, finding information on the Internet seemed almost magical, that if you had access to the Internet you would never feel "stupid" again because you could always look up information. In contrast, those with adequate health literacy and the ability to use the Internet to find health information also reported a number of difficulties or barriers to getting accurate health information from online sources. This theme likely had the most variability across participants and is a theme where a participant's age or socioeconomic status might play a substantial role in the participant's ability to improve this skill. Codes within this theme included the use of search engine strategies in an effort to get more

narrow results, having the skills to compare the information in many different online resources to get an “answer,” navigating online search results (e.g. choosing which page to click on), and extracting information from online forums.

A less than adequate health literacy participant discusses that, these days, information generally comes from the Internet; however, he has not yet learned computer skills. This can sometimes make him feel inadequate, as if he should know more than he does.

Well...since I'm not astute in computers yet. You know, it's gonna be a problem. Because if you want to know things, you go on the Internet now, but if you're not astute to it, it's gonna be hard to get – information and cuz uh – the doctor's cuz like, why didn't you go on a computer – why didn't you go on the Internet? So, if you're not astute in that yet, you might not get the information you need, you know?

(Patient #2, Male, 50 years old, African American, Low health literacy)

This participant also had less than adequate health literacy but did identify as having computer and online information seeking skills. They report having difficulty with the use of search engines.

If you don't know exactly what you're looking for, then yeah, you can be - you can yourself in a circle, sure, with the search terms – words or something like that – I could probably – take some refresher courses on that on searching and stuff like that, but that's all I could tell ya.

(Patient #8, Male, 52 years old, White and Native American, Low health literacy)

Still other participants with less than adequate health literacy, perhaps those who were younger, had more experience using the Internet (mostly on a mobile device) to look for health information and thus would suggest this as a way of getting information on any topic.

[When asked about advice they'd give to a friend about finding health information] I'd tell them to log into Google. Google'll show you the way. They'd just need to know how to spell it – but not really cuz – if you don't know how to spell it, it'll just pop up. Google is smart – it'll help you, even if you misspell a word. And it'll help you spell it. And it will pop up the right way. As long as they know what they talkin about, they can type it in – they got it – they find it.

(Patient #9, Female, 28 years old, Native American, Low health literacy)

Some participants, such as the less than adequate (12) and the adequate (20) participants below, proposed that finding health information online might be tied to the generational concept of being a “digital native.”

Well my mom – especially computer training – computer training - basic – the basic, just like, how to run a computer. How to turn it on – that's a basic. How to type or whatever – that's the other thing they'd need to have computer knowledge – or website knowledge, or whatever.

(Patient #12, Female, 41 years old, Hispanic, Low health literacy)

It's almost like they [people who don't regularly use a computer] have a different brain. It's just completely foreign, it's like you know, they think that hovering a mouse pointer over something automatically there like, oh why isn't it taking me there? It like, mom you have to click.

(Patient #20, Male, 32 years old, Asian, Adequate health literacy)

Similarly, another health literate participant attributed his age (40 years old) to having a “foot in both worlds” of information seeking, meaning he considers himself good at finding information online but also through offline resources. He learned how to improve his information searches online through advice websites such as Life Hacker. It seems that this participant, with increased access to the Internet, was able to learn over time some different ways of using the Internet more effectively.

When using Google I try to use a lot of the modifiers that you can use to separate out the content. Um, I think I'm a good, an adept search engine user. And I can narrow it down so I'm not getting a bunch of crap.

(Patient #21, Male, 40 years old, White, Adequate health literacy)

Health professionals also discussed the potential for variability in online health information seeking skills across patients. Most health professionals reported advising their patients to not use health information from the Internet while others knew that, at least for some patients, getting health information from online sources was cheap and readily available. This comes with the caution of online information source and content credibility, though.

I usually always tell people not to believe what they read online. If it's something basic like a sty or an itchy throat – something not life threatening at all – you might find a home remedy online, but if not, you need to go to the doctor...basically the Internet these days [is where people go for health information].

(Health Professional #3, Female, 34 years old, Hispanic)

Sometimes people will default to something that's comfortable and that they're already using. And so if you have someone who is comfortable using the Internet and those other types of resources, so it's easier for them to get online and actually make something of the information they've received. But then we have other folks who just aren't comfortable doing that and they may not be comfortable in a doctor's office or may not have had experience with health providers that are positive and helpful. And so what makes us think that they're gonna return, you know what I mean? I like to provide different opportunities to people.

(Health Professional #4, Female, 31 years old, White)

Another health professional suggested, “Not everybody knows how to access the Internet. Much less access information from it. So even just that basic skill of turning on a computer and being able to get to the information.” It is clear that health professionals do not necessarily uniformly agree about how to handle patients with less than adequate health literacy and their use of the Internet to find health information.

*Spatial Navigation.* Participants with less than adequate health literacy commonly reported having to *physically get to* health information, rather than having the information they needed come to them. These participants often had to take a bus or walk to health clinics in order to have their health questions answered. Sometimes this was a trial and error process, where even just to determine if a clinic accepted a specific type of health insurance, a participant might have to walk many miles to that clinic. Participants described waiting for busses and missing appointments, not knowing where clinics were located, and other barriers to physically getting to health information. Having an understanding of one's spatial environment was an essential skill needed for these participants. This theme was not described by those having adequate health literacy; however, health professionals did recognize that those living in poverty may be less likely to get the health information they needed due to not being able locate a health clinic in their area. This theme is outlined by less than adequate health literacy patient participants below.

Uhhh – I don't have any friends – but I have people on the bus that ask, where the clinic is this – and I was on my way and I got off and showed em to. Sometimes I would get off, and if I need to go this way, and they need to go this way, well I can help them take 'em over – show 'em where it at. Take 'em – in the days – walk with them, talk with them, til they get to the clinic – and once they go in there – I take off. And I tell them, before I take off – before the way we came in, that's the way you go out to catch the bus.

(Patient #10, Male, 52 years old, Hispanic, Low health literacy)

The only one that's really hard to find – is the dentists – and that's because there are so many. Like if you say, Smile Center, you're gonna get like 30 different smile centers – you're gonna have to know exactly what location, otherwise you're gonna have to call them up and say, is this such and such location, you know, they'll give you the number, but other than that, you'll



have to know the location...Uhhh...I pretty much...pretty much...go by my zip code and it'll pop up like, maybe if there's 3 or 4 of them in that area – then you figure out well, this is Airport, or this is Springdale, you know, this is MLK – which one is closer to me, so I would know to go straight to the MLK number.

(Patient #15, Female, 37 years old, African American, Low health literacy)

These seven themes reflect commonalities across the present study's sample of patients of adequate and less than adequate health literacy and health professionals. Conducting one-on-one interviews sheds light on the skills these individuals see as being required for finding health information. This lends face and content validity to the next step of the present study. In Phase Two, these themes or skill sets will be transformed into quantitative measurements in an effort to identify and measure the components that comprise the first facet of health literacy – finding health information.

## **4.2 PHASE TWO RESULTS**

### **4.2.1 Phase Two Participant Characteristics**

After removing participants who filled in the survey with implausible responses (e.g., writing “x-ray” when that was not relevant to the question, or writing “idk” [I don't know] for all free response questions, n=68), a sample of 335 participants remained. Four of these participants were not 18 years of age or older and were removed from the sample. After removing these participants, the final sample used for the present study was 331 adult participants (N=331). A sample size of 300 or more participants is seen as adequate for conducting factor analysis with a large number of variables (Kass & Tinsley, 1979; Comrey & Lee, 1992; Tabachnick & Fidell, 1996; Field, 2000). Perhaps as a result of using a research participant panel, there was very little missing data from the research

variables of interest, with the question, “In general, if you were having a conversation with another person about health, please rate the level of difficulty you would have with *responding to what the other person is saying about health,*” which had four missing responses (1.0%). Missing values for each item were substituted with the mean for that item.

Of the remaining participants, 57.4% were female and 72.8% were White (a complete demographics chart can be found in Appendix D). The average age of the participants was 41.96 years (SD=16.36). A majority of the participants had at least some college education (84%) and 92.7% of the sample reported being able to speak English “very well.” A majority of the participants had health insurance (86.1%). On average, participants in this sample did not have to visit the emergency room often in the past 12 months (M=0.50 times, SD=1.66, range=0-20 times), but most did visit doctors, nurses, or health professionals in the past 12 months (M=4.84 times, SD=6.80, range=0-50 times). Participants indicating a high (20+) number of health professional visits in the past year often noted that the number was more than usual because they were pregnant or became a new mom within the past year. Perhaps given the middle-aged adult sample, sensation seeking among the sample was low, ranging, on average, from 1.92 (SD=0.92) (“I like wild and uninhibited parties.”) to 2.64 (SD=0.80) (“I like to have new and exciting experiences and sensations even if they are a little frightening.”) on the 4-point Likert scale. However, these items were normally distributed and exhibited adequate variance, ranging from 0.634 for the new and exciting experiences item above to 0.852 (“I sometimes do ‘crazy’ things just for fun.”).

#### **4.2.2 Exploratory Factor Analysis**

The purpose of Phase Two was to determine, using a quantitative methodology, a set of factors that reflect the skills needed for an individual to successfully find health information. As such, the factors of interest included in this analysis were Knowing When to Search, Credibility Assessments, Reading Ability, Finding Numerical Information, Interpersonal Seeking, Finding Health Information Online, and Spatial Navigation. Additionally, the concept of Sensation Seeking, a personality trait variable, was included for discriminant validity purposes, as described in the Methods section. Items for each of these factors were generated for the present study based on findings and language from the Phase One interviews. Means, standard deviations, and skew and kurtosis values for each variable are located in Appendix C.

A correlation matrix that included all of the items was generated in an effort to give initial insight into how the survey items clustered together (see supplemental file). A majority of the items shared positive and significant correlations. Among the significant correlations, values ranged from  $r^2=0.110$  (between being able to find numerical information in a health insurance benefits chart and the frequency with which the participant, when looking at health information, considers the author's purpose for writing that information) to  $r^2=0.837$  (between being able to find numerical information in a magazine article and being able to find numerical information in a newspaper article). The range of these maximum and minimum significant correlations suggests a lack of multicollinearity (items extremely correlated, i.e. over 0.90) or singularity (items

share a perfect correlation) (Field, 2000), making this correlation matrix appropriate for use in factor analysis.

Close examination of the correlation matrix offered several suggestions about individual items. First, reverse coded items tended to be inconsistent in how they correlated with items within the same proposed factor and across other factors. For example, reverse coded items for the Credibility Assessments factor often shared negative correlations with the ability to find text information in a number of health documents, such that participants reporting a greater ability to find text information in a health document were also those who indicated that, when looking at health information, they trust that printed information is true “all of the time,” which is thought to suggest a lack of skill in one’s ability to judge health information critically (significant  $r^2$  ranged from -0.118 to -0.237). Many of the reverse coded items shared similar surprising correlations or correlated across other items inconsistently, sharing some positive and some negative correlations, of which some were significant while others were not. This is not entirely unexpected, in his discussion of survey construction, DeVellis (2003) suggests that reverse coded items can occasionally be tricky or confusing to participants – thus they may answer these items inconsistently, mismark an answer, or ignore the change in wording of the questions.

In addition, inspection of the correlation matrix provided initial insight into a potential yet unexpected relationship between sensation seeking and reverse coded items included on other factors that might be seen as “putting faith in someone else” to have done the work that was needed. For example, participants with greater sensation seeking

scores across these items exhibited a negative correlation with some credibility items such as “feel[ing] confident that health information generally comes from a credible source” ( $r^2$  ranged from -0.110 to -0.214).

Finally, examining the correlations between all items included in the self-report portion of Phase Two suggested that one item (“When looking for health information online I typically start at the top of a search list and work my way down the list until I find what I need.”), might be considered a poorly worded item. This item could be seen as containing two clauses: 1.) that the participant starts at the top of a search list and 2.) that they work their way down the list until they find what they need. This item was initially developed to reflect the idea that participants with a greater ability to find accurate and reliable health information online would look at a list of search results and pick one that was most relevant to them, rather than just clicking on the first link at the top of the list. However, given the inconsistent correlations this item shared with other items in the survey, it should be noted that many people would start *looking* at information at the top of a search engine result list; however, they might read that information and decide that the first link is not what they were looking for and move down the list before clicking.

Given the confusing nature of this item, it was not included in the exploratory factor analysis. However, it was decided that all other items would be included for this analysis. It was determined that the reverse coded items mentioned above would be included for the initial factor analysis as these items occasionally did share significant correlations with other items, even if not in the expected direction. For example, despite

the Credibility Assessments item mentioned above that suggests the participant trust(s) that printed information is true “all of the time,” which correlated in the opposite (negative) direction with the items regarding being able to find health information in a variety of health documents, the credibility assessment item correlated positively and significantly with other reverse coded credibility assessment (e.g.,  $r^2$  ranged from 0.286 to 0.619). It could be that, despite reverse coded items exhibiting inconsistent correlations with some of the other items on the survey, these items could yield adequate reliability within each other. It could be that these items do reflect a skill different from what was initially expected.

Exploratory factor analysis (EFA) was used in the present study to determine a set of skills needed for an individual to find health information. The interviews in Phase One were used to generate a majority of the items in the Phase Two quantitative survey; thus, many of these quantitative items have not previously tested. EFA can be used to detect a subset of factors that underlie a given set of survey items. It could be that the items included in the survey indeed reflect the seven factors of interest outlined by participants in Phase One; however it is difficult to make this judgment without first looking at the relationships between the survey items.

EFA was initially performed using all of the survey items of interest, with one item removed (as described above, item: “When looking for health information online I typically start at the top of a search list and work my way down the list until I find what I need.”). Of the factor extraction methods available in SPSS, maximum likelihood was selected as it the estimation method most commonly used in other statistical packages

such as AMOS and Mplus that will be used for subsequent analyses. Correlations were expected between items and factors, given the nature of the item content (a focus on skills for finding health information), and as such an oblique promax rotation was employed for all EFA analyses.

As suggested by Field (2000), another close examination of the correlation matrix was performed and items with a majority of non-significant correlations were removed from the analysis (nine items removed, see Appendix E). These items included three reverse coded items. This is consistent with the previous inspection of the correlation matrix, which suggested that several of the reverse coded items did not correlate in the expected direction. In addition, the six sensation seeking items were removed given the large number of non-significant correlations with other survey items. These non-significant relationships could likely suggest that the items thought to reflect skills for health information seeking do in fact measure concept(s) different from sensation seeking. The sensation seeking items were included as a check for discriminant validity and as such were not expected to correlate with the skills items.

After removing non-correlating items, EFA was performed a second time to yield improved analyses. The correlations between survey items were again examined. As a result of this examination, an additional five survey items were removed from the analysis (Appendix E) due to a small number of correlations with other survey items. EFA was then performed a third time. Following a close inspection of the correlation matrix and determining that no additional items should be removed from the analysis, the list of communalities was scrutinized for items with low extraction values, which suggest

that an item has only a small amount of variance shared with the other remaining items (Field, 2000). From the remaining items, three had small communality values after extraction, ranging from 0.111 to 0.172, and were thus removed from the analysis (Appendix E). All other items had communality values after extraction of 0.243 and greater. It should be noted that these three items were again reverse coded items and tended to correlate inconsistently across the other survey items.

As a result of these inspections, a total of 51 items were retained for the final EFA. The EFA produced a total of nine factors having eigenvalues greater than Kaiser's recommended 1.0 criterion (Kaiser, 1960). Only one item loaded on the ninth factor (the ability to find text health information in a medical bill) while several items loaded onto each of the other eight factors. As such, the resulting final EFA was restricted to having eight factors. An examination of the scree plot produced for this EFA suggested that five factors should be extracted; however, when this was performed, items loaded onto factors in a way that collapsed conceptually different items. For example, all of the items reflecting Reading Ability and Finding Numerical Information loaded onto one factor in a five-factor approach. Given that seven factors were originally expected given the findings from Phase One, it was determined that the five factors suggested by the scree plot might muddle conceptually different factors. Moreover, only 55.57% of the variance was accounted for using a five-factor extraction. Subsequent inspection of the correlation matrix, the rotated pattern matrix, and the communalities produced by the EFA encouraged the researcher to rely on face validity and Kaiser's eigenvalue recommendation to determine the number of factors to extract in the final EFA.



After factor extraction 62.35% of the variance was accounted for across the eight factors (see Appendix F for the percentages of variance accounted for by each factor before and after rotation). The KMO statistic for this EFA was 0.936, indicating the presence of a “superb” correlation matrix (a matrix that contains a strong pattern in correlations between items), and thus would likely produce discrete and consistent factors (Kaiser, 1970; Kaiser, 1974; Hutcheson & Sofroniou, 1999). Additionally, the diagonal of the anti-image matrix displayed correlations well above the required 0.5, further suggesting that no additional items should be removed from this EFA (Field, 2000). Another important matrix inspection criterion is to ensure that the correlation matrix used in the EFA is not an identity matrix (a matrix where none of the items correlate with one another, thus suggesting that factor extraction is not appropriate) (Field). This test was significant ( $X^2=13474.01$ ,  $p<0.001$ ) and thus the matrix was thought to not be an identity matrix.

The factor loadings presented in the pattern matrix for the eight retained factors are presented in Appendix G. Of the items included for the analysis, three items did not yield substantial loadings (around 0.4 to 1.0) on any of the factors (Appendix E), leaving a remaining 48 items to load across eight factors. Based on extraction, the amount of variance accounted for by each factor ranged from 38.97% (factor 1) to 1.40% (factor 8). Each of the factors were re-named given the items that tended to load on each factor:

Factor 1: Finding Numerical Information – Items loading on this factor consisted mostly of those reflecting one’s ability to extract numerical information from a variety of health information types. Two items reflecting one’s ability to extract text information

from a medical bill and from a chart or graph also loaded highly on this factor, likely due to the quantitative nature of medical bills and graphs or charts, compared to the other types health information types on the survey (e.g. a textbook), which loaded on other factors. It is likely that this factor reflects a skill for finding information having to do with numbers.

Factor 2: Interpersonal Seeking – Items were specifically created to reflect a skill for finding information within conversations about health. These items all loaded on the same factor as expected.

Factor 3: Credibility Assessments – The items reflecting one’s ability to check health information for source and content credibility also correlated together as expected. This factor reflects one’s skill for being able to determine whether the content of a piece of health information is accurate and reliable, as well as be able to determine if the information is coming from a credible source. Interestingly, all of the reverse coded items for this hypothesized factor were eliminated from the EFA due to poor correlations with many of the other survey items. However, the reverse coded items did tend to share a relationship with the Sensation Seeking items, where individuals with a greater tendency for sensation seeking reported that they were more likely to “trust that printed information is true” ( $r^2=-0.158$ ,  $p<0.005$ ), “stick with the first thing I read” ( $r^2=-0.208$ ,  $p<0.001$ ) and “feel confident that health information general comes from a credible source” ( $r^2=-0.170$ ,  $p<0.005$ ).

Factor 4: Health Information Seeking Experience – This factor included a number of items from two constructs outlined by Phase One interviews: Finding Health

Information Online and Knowing When to Search. These items could culminate together to form what is most likely a health information seeking experience for this audience of mostly educated, English speaking, majority White adults in the U.S. who have a knowledge of their own health and understand their health history. At the same time, they are confident in being able to look for health information online and thus can look for health information that is relevant to them in a given health situation.

Factor 5: Spatial Navigation – This factor reflects a skill described by many of the less than adequate health literacy patients in the Phase One interviews, where being able to get to a physical location by using maps, street signs, landmarks, and directions was often necessary for getting health information.

Factor 6: Labels – Interestingly, the items reflecting one’s ability to find both text and numerical information in medicine and nutrition labels correlated with one another. It could be that a specific skill is needed for finding information within a label, where specific intent is given to how information is presented to a viewer.

Factor 7: Text Within Text – Items reflecting one’s ability to find text information within paragraphs held with one another. These items included finding text information in newspapers, paragraphs of instructions, magazine articles, textbooks, and health pamphlets. These pieces of health information may require a viewer to scan through a great deal of text before locating desired information; thus employing a different skill than the previous factor, where the information contained in a label might be a unique type of scanning for or extracting of information.

Factor 8: Health Information Challenges – The items for finding text and numerical information in the fine print of a drug advertisement and in a research article correlated together. These two pieces of health information may be seen as the “most difficult” pieces of information from which health details could be found. For now, this factor is labeled as “challenges” because it is not known whether these items came out separate from finding text and numerical information in other forms of health documents due to the greater tendency for these to include medical terminology or “jargon” or for another reason.

It should be noted that six items exhibited substantial loadings on two factors. In these cases the items were included with the factor that made greater sense conceptually, rather than solely relying on the value of a factor loading. As a result, the items for an individual’s ability to find numerical information in the fine print of a drug advertisement or a research article were included on the Health Information Challenges factor. Also, an individual’s abilities to find text information in a newspaper and in a magazine were included with the Text Within Text factor with the other items dealing with one’s ability to find text information in long paragraphs of health information such as a health textbook. One’s ability to find text information in a health insurance benefits chart was included with the Finding Numerical Information factor. Finally, one’s ability to find numerical information in a medicine label was included on the Labels factor with the other items pertaining to one’s ability to find text and numerical information in both medicine and nutrition labels.

Given the selection of oblique rotation, the eight factors produced were permitted to correlate. It is likely that many, although perhaps not all, of these skills correlate substantially and in a positive direction with one another as they are all thought to contribute to health information seeking. Indeed, large correlations were detected between the factors, which ranged from the lowest correlation between Health Information Challenges and Health Information Seeking Experience ( $r^2=0.207$ ) to the correlation between Health Information Seeking Experience and Interpersonal Seeking ( $r^2=0.643$ ) (see Appendix H for a factor correlation matrix). These correlations suggest that, although related, the factors do not show the extremely high correlations thought to reflect multicollinearity ( $r^2 \geq 0.90$ ) and thus likely reflect different, yet related skill sets.

#### **4.2.3 Reliability Analyses**

The reliability was then examined for each of the eight factors to determine the extent to which the items of each factor measured that one concept. This internal consistency was high for each of the factors (Appendix I). Overall, items included in Phase Two produced eight factors, of which are thought to reflect eight different, yet highly related skills for finding health information.

## **5.0 DISCUSSION**

### **5.1 IMPLICATIONS FOR IMPROVING HEALTH LITERACY AND HEALTH OUTCOMES**

Health literacy, a person's ability to find, understand, use, and communicate about health information in an effort to make informed health decisions (Berkman, Davis, & McCormack, 2010), plays a vital role in health outcome implications. Having less than adequate health literacy is linked to overall poorer health (IOM, 2009; Nielsen-Bohlman et al., 2004), in addition to a host of other health-related implications (e.g. having difficulty communicating with health professionals; Williams et al., 2002). Negative health outcomes associated with low health literacy yield billions of dollars in healthcare costs to the U.S. economy (Vernon et al., 2007). Despite these important health issues, an estimated one-third of American adults are thought to have low health literacy (Kutner et al., 2006; Paasche-Orlow et al., 2005; Williams et al., 1995), a prevalence that is thought to be higher among those who did not complete high school, racial/ethnic minorities, and the elderly (Nielsen-Bohlman et al., 2004; Paasche-Orlow & Wolf, 2007). Given the prevalence and plethora of negative health outcomes associated with having low health literacy, intervention work that aims to improve these skills is needed. While there have been many health literacy scales developed in recent years (Haun et al., 2014), a consistent definition, with corresponding conceptualization and measure, are needed prior to generating health literacy interventions so that 1.) changes in health literacy can be detected as a result of interventions and 2.) so that results can be compared across health literacy studies.

As such, the purpose of this piece was to propose a model of the facets that are thought to drive health literacy (Appendix A), based on an existing definition of this concept (Berkman, Davis, & McCormack, 2010). This four-facet approach is the first of its kind and may shed light on the many skills that comprise health literacy. A study in which the skills for the first facet of health literacy, finding health information, were explored was generated as an initial step towards creating measurement tools for each of the four facets proposed in the health literacy model. This study is meant to serve as a protocol for future studies that will examine each of the other three health literacy facets. After giving considerable attention to each of these facets, a measurement tool that is capable of assessing change in health literacy as a result of interventions, rather than acting as a brief screening measure (putting patients into a “health literate” or “low health literacy” group) (IOM, 2009), can be created. This will not only improve the ability to tailor health literacy interventions to the needs of patients by being able to determine the specific areas of health literacy in which patients struggle, but it will also allow researchers and health professionals to have a better understanding of the relationships between health literacy facets and how this might drive health outcomes.

## **5.2 WHAT SKILLS DOES AN INDIVIDUAL NEED TO FIND HEALTH INFORMATION?**

The present study aimed to answer one key research question: What skills does an individual need to find health information? Seven themes were outlined by patients and health professionals as skills needed for finding health information (Phase One): Knowing When to Search, Credibility Assessments, Reading Ability, Finding Numerical Information, Interpersonal Seeking, Finding Health Information Online, and Spatial

Navigation. These themes were then translated into eight factors through quantitative survey data that used the qualitative interview themes as the basis for generating survey content (Phase Two). Three of these eight factors were initially generated through a review of existing literature (Finding Numerical Information, Interpersonal Seeking, and Credibility Assessments) and subsequently supported through Phase One interviews and Phase Two quantitative data. The factor of Spatial Navigation was initially found in Phase One and then supported in Phase Two. Finally, the other four factors generated from Phase Two were not considered after reviewing the literature, nor were they outlined in Phase One interviews (Labels, Text Within Text, Health Information Challenges, and Health Information Seeking Experience); however, Health Information Seeking Experience was comprised of items identified through Phase One themes of Finding Health Information Online and Knowing When to Search.

<b>Information Type</b>	<b>Information Amount</b>	<b>Method</b>
Credibility Assessments	Knowing When to Search	Reading Ability
Finding Numerical Information	<i>Health Info. Seeking Experience</i>	Interpersonal Seeking
<i>Text Within Text</i>		<i>Spatial Navigation</i>
<i>Health Information Challenges</i>		<i>Finding Health Info. Online</i>

Table 5.2: Health Information Seeking Themes Through Research Findings

Given these findings, the framework from Lambert and Losielle (2007, p.1013) that was initially used to outline the existing literature on finding health information can



be updated to reflect the skills uncovered in the present study (where italicized information indicated skills found in the current study, see above).

Taken together, it seems that individuals have a variety of method skills they might employ to get health information from different venues (reading or scanning for text and numbers, asking others, navigating one's environment, and seeking online). Additionally, it may be that different types of health information or content (credible/marketing, labels, paragraphical text, numerical, and medical jargon) each require a unique skill for finding information within these types. Also, having the skills for managing when and how much of a search process takes place before health information is found may be distinctly different from the aforementioned skills.

In comparison to the findings from Jordan and colleagues (2013) (whose methodological design was adapted for the current study), the skills extracted in the current study are much more specific than the broad abilities they identified. In the development of HeLMS, Jordan and colleagues aimed to uncover all of the "content areas" that comprise health literacy, rather than using an existing definition to help categorize the broad abilities initially (the current study used the four-facet approach from the Berkman, Davis, and McCormack, 2010 definition). As such, Jordan et al. only found two skills (knowing when and where to find health information and verbal communication skills) that might be seen as specifically devoted to finding health information. These skills were uncovered in the present study, in addition to a number of other skills thought as needed to find health information, which is just one piece of health literacy. The more broad approach taken by Jordan and colleagues may be seen as more

efficient (health literacy examined as one unit rather than four), but it is clear that in doing this they did not detect several of the other skills that might contribute to health literacy.

Given the exploratory nature of the current study, research that confirms the importance of each of these skills is needed. In the remaining sections, I will argue for the conceptual relevance for each of the skills generated in the present study and will summarize existing literature for each skill. Then, I will outline propositions for future intervention work in these areas (however, this is contingent on whether a re-test of the items included in this measurement tool indeed reflect results similar to those included in the present study). Finally, I will outline the limitations imposed on this study and conclude by summarizing the contributions of this piece to the development of health literacy and intervention work aimed at health promotion.

### **5.3 CONCEPTUAL RELEVANCE OF EXTRACTED SKILLS**

#### **5.3.1 Finding Health Information Online**

In Phase One, two themes, Finding Health Information Online and Spatial Navigation were identified through qualitative interviews but had not been hypothesized as unique skills for finding health information, given a review of the previous literature. Health literate participants discussed the skill of Finding Health Information Online as something that they utilized often (looking for health information online was, without a doubt, the most common place to get health information for this group within the sample); yet, they were often self-proclaimed non-experts with this skill, admitting that they could use more search engine modification techniques (such as quotes and dashes)

and look for information from better quality online sources (such as research articles or government/organization-supported information), rather than information coming from popular websites such as Web MD or online forums (this clearly overlapped with the hypothesized skill of credibility assessment). Some participants with low health literacy discussed looking for health information online but their ability was clearly less developed than that exhibited by health literate participants. For example, participants with low health literacy often stated that all it took to find health information online was the ability to type a health topic into a search bar – often relying on Google to “show them the way” in terms of spelling and content (see the quote from Participant 09 in Results). Health professionals who worked with low health literate patients confirmed that these patients were often informed by “bad” (factually inaccurate or marketing) information that the patient found online.

The rate of health information seeking online across patients of varying levels of health literacy is not surprising. In 2012, more than half of American adults reported going online in the past year specifically to find information related to health topics. Many adults (about one-third) report using the Internet as a tool for self diagnosis or for the diagnosis of others (Pew Research Internet Study, 2013). Similarly, health information on the Internet is often thought to be correct or believable (Houston & Allision, 2002). Although searching for health information online may initiate greater comfort and conversation with a provider about personal health (Ybarra & Suman, 2008), especially among those with poorer health (Houston & Allision, 2002), this activity could also result in a number of drawbacks: A systematic review of studies focused on health-

related websites suggests that these online resources are often described as being incomplete or inaccurate, and good health-related websites can be hard to find (Eysenbach et al., 2002).

Given the prevalence of health information seeking online, it is surprising that this skill did not emerge as a separate factor through the Phase Two EFA. However, it could be this online seeking ubiquity that allowed the items for this factor to correlate closely with the skill of understanding one's own health and health history. Perhaps health information seeking online is such a go-to mode for getting health details that it could be seen as part of one's ability to maintain their own health and/or the health of others (see also 5.3.4 for a discussion of the Health Information Seeking Experience variable).

### **5.3.2 Spatial Navigation**

Another surprising finding that was initially generated in the Phase One qualitative interviews but not through a review of the literature was the skill of Spatial Navigation. Unlike Finding Health Information Online though, this skill was supported as a unique factor through EFA. In Phase One, health literate patients and health professionals did not identify this as a skill needed for health information seeking; however, it was clearly an important factor for those having less than adequate health literacy. For individuals needing to take public transportation or walk to a health clinic (or other physical location) for health information, the ability to use a map or navigate directions/landmarks in an environment may be essential. This is not to say that patients with low health literacy are the only ones who experience challenges with Spatial

Navigation; however, they may be more likely to need this skill when looking for health information.

Previous research in this area suggests that Spatial Navigation, similar to finding health information online, has the potential to change over time, perhaps given experience with navigation tasks. Spatial Navigation, when self-reported as done in the present study, tends to positively correlate with objective behavioral, spatial task completion such as re-evaluating one's direction in an environment (i.e., one's relationship to objects in the environment) and navigating paths by mentally calculating spatial distances. As such, greater Spatial Navigation skills correlate positively with fewer errors made in the area of "spatial learning," specifically through direct experience (Hegarty et al., 2002). In the work done by Hegarty and colleagues, direct experience navigating through a new environment exhibited a stronger correlation with Spatial Navigation than did experience with a new environment through media such as watching a video or looking at a virtual environment map. Given this, individuals who regularly need to determine spatial routes to new places would likely perform better at this task than an individual who uses a mobile device or navigation service to reach a new destination.

Jordan (2013) and Osborne (2013), in their respective studies aimed at building measures of health literacy, note that it is important to not drop focus on having a range of items thought to tap a variety of patient abilities – including very difficult and very easy items. The concept of Spatial Navigation, while extremely important for patients of low health literacy, might be less relevant to health literate patients for finding health

information. However, this does not mean that health literate patients would perform well on these items necessarily. As it stands now, Spatial Navigation should be maintained in future iterations of this study before removing or revising this concept. Generally, more research is needed about this topic and its relationship to getting health information and health services.

### **5.3.3 Looking for Text and Numerical Details**

Another unexpected finding in the present study was that the skills needed to look for information across different types of health text loaded on several different factors not identified through previous literature or in patient and health professional interviews. The factors, Text Within Text, Labels, Extracting Numerical Information, and Health Information Challenges, suggest that unique skills might be needed to (respectively) scan for text within other text information, extract points from information that has been organized, look for numerical versus text information, and perhaps find content within health information that contains medical jargon rather than plain language.

Participants in Phase One tended to emphasize one's ability to read as a skill necessary for finding health information. However, given the nature of the sample included in Phase Two (research participants from an online participant pool), it was assumed that participants had the ability to read and participants were instead asked to report their ability to find text-based information from a variety of health texts. This edit was seen as taking the Phase One theme into account while also re-directing the assessment of the skill to be more consistent with the goal of *finding* health information. Looking for text information within paragraphical health texts including a textbook,

health information pamphlet, magazine article, instructional paragraphs, and a newspaper article were found to correlate with one another as a result of the Phase Two EFA.

Finding a piece of text information within paragraphs of text such as those mentioned above likely requires the skill of successfully scanning through “unnecessary” information, rather than reading ability alone. Research in the area of website usability and user experience testing that employs eye-tracking technology suggests that oftentimes website pages include “too much information,” where the text information on the page is presented as one block of text, rather than giving the reader natural breaks in the information. In one study, this produced a high rate of participant drop out (participants did not read past the first line of text). Difficulty in scanning across text is easily detected when using eye-tracking technology, where longer scanpaths (visually moving through a piece of content before moving to another piece of content, which is different from truly *reading* the content) may be suggestive of an individual who is performing less efficient scanning (Ehmke & Wilson, 2007). Similarly, in the process of both scanning and reading, words are skipped between 15 and 65% of the time in an effort to conserve processing capacities. This skipping of words stems from detecting the frequency of a given word within the text (e.g., how often does a particular word occur in the text, where words that appear more often are also more likely to be skipped) and how related the word is to the overall context of the material (Rayner, 1998).

As such, it may be that the paragraphical health texts that correlated together in Phase Two of the present study require the unique skill of text scanning for relevant content. This skill could be explored further by implementing scanning-oriented tasks

paired with the use of eye-tracking technology. This technology could detect patterns in a viewer's attention and visual gaze in relationship to different paragraph lengths, across the health texts that correlated in the present study, and with text about different health topics to determine if additional skills other than text scanning are needed to find health information in paragraphical texts.

In juxtaposition to scanning through paragraphs of text in search for a piece of information, finding details within a label may require a different skill from health information seekers. Finding health information in medicine and nutrition labels correlated highly in Phase Two of the current study, but were not uniquely identified as important skills in Phase One interviews. In the U.S., over-the-counter drug labels and nutrition labels must adhere to formatting guidelines as outlined by the U.S. Food and Drug Administration (FDA). Having specific requirements for these labels promotes ease of product regulation and restricts claims made to a consumer. Close attention and monitoring is dedicated to the inclusion and design of the information contained in these labels.

It may be that this effortful organization, rather than presenting the information in a large block of text, could make finding health information in these labels easier than other modes of information presentation. Generally, efforts to improve the layout, navigability, and quality of health information are needed. Although it is known that the layout of health information is a critical component for seeking and finding health information, it is not often included as a focus of health promotion research (Aakhus, 2007; Aakhus, & Jackson, 2005; Joffe, 2008). Research suggests that health information



should also aim to include a mix of textual information as well as pictures in an effort to produce greater attention and health information recall (Houts, Doak, Doak, & Loscalzo, 2006). Additionally, previous research suggests that the application of design principles, paired with a medium level of design complexity (the inclusion of only a few objects on a page, color contrast, etc.) can produce more positive consumer evaluations and greater attention given to the content than content that is visually complex (Champlin et al., in press). Findings from the current study suggest that the skills needed for finding health information that occurs in paragraphical text and that presented in the form of a label are perhaps abilities that should be measured and intervened upon using distinct efforts.

In addition to having skills for locating text information within a body of text and identifying information presented in a label format, results from the current study identified that finding numerical information, or information in a document containing quantitative information (e.g., a medical bill), could require a skill different from those identified above. The concept of numerical extraction was initially identified through the existing NAAL literature, which suggests that an individual may process text and quantitative information in different ways (Kutner et al., 2006; Rudd, 2007).

Generally, American adults struggle when working with numbers in a health context and health “numeracy” continues to emerge as potential factor for understanding health outcomes (Woloshin et al., 2001; Estrada et al., 2004; Reyna & Brainerd, 2007). As such, it was not surprising that finding numbers-based information was a skill identified as different from the skill for finding text-based information. While the application of design principles can help organize text-based information, other research

suggests that patients continue to struggle with information from nutrition labels, perhaps due to the quantitative nature of much of the content included on the labels (Rothman et al., 2006).

Also, finding information in a research article and in the fine print of a drug advertisement shared strong, positive correlations. It could be that finding information in these documents is particularly challenging due to the higher frequency of medical terminology; however, this cannot be determined for certain given the results from the present study. Interestingly though, several health literate patients in the Phase One qualitative interviews stated that they might search for an academic or research-oriented piece when looking for health information, as many of them had previously worked occupations where they were responsible for navigating peer-reviewed literature and corresponding databases. Yet, many of them admitted that the information presented in these articles was not necessarily in a language they could understand.

Previous research supports this supposition; in one study a review of direct-to-consumer (DTC) pharmaceutical advertisements was conducted using readability word processing software. This work determined that the readability of these advertisements was significantly more challenging than any other type of printed advertisement. DTC ads contained, on average, 214 words per advertisement. Finance advertisements contained the next highest number of words at only 130 words per ad, on average. Moreover, DTC ads included in the study ranked at an 8<sup>th</sup> grade reading level and were only exceeded by software, corporate image, and telephony advertisements (Sheehan, 2006).

While finding health information in challenging text such as DTC pharmaceutical advertisements and research articles was elicited through the current study, it should not be expected that all consumers have a health professional's level for understanding medical terminology. This would be unreasonable and unfair to consumers. However, in subsequent studies, these items may be retained to demonstrate an upper level of health information seeking in an effort to minimize ceiling effects (Jordan et al., 2013; Osborne et al., 2013).

#### **5.3.4 Skills Identified Through Previous Research and Supported by Phase One and Two**

Other factors generated through the current study's Phase Two were expected given previous literature and the Phase One interviews with patients and health professionals. The factors of Interpersonal Seeking, Credibility Assessments, and Health Information Seeking Experience were expected to emerge as skills needed for health information seeking, given the review of previous literature.

Most commonly, the skill of Interpersonal Seeking was identified as necessary for talking with a doctor. Patient participants in Phase One across health literacy levels reported having difficulty with asking a doctor questions and/or understanding what a doctor was saying. Patient-provider communication is a quickly expanding area of research in which a number of interventions have been recently developed. One is example is Ask Me 3; a health campaign aimed at patients to think about three important questions – “What is my main problem?” “What do I need to do?” and “Why is it important for me to do this?” – if any of this information is unclear, patients are

encouraged to ask their provider these questions. This campaign has already exhibited positive results for patient-provider communication (National Patient Safety Foundation, 2014; Six-Means et al., 2012). A similar program produced by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) created SPEAK UP, an acronym that focuses on speaking, paying attention, educating oneself, asking a family member for help, knowing what to do, using healthcare facilities, and participating in one's own care (Sparks & Villagran, 2010).

Despite a lack of prevalence in Phase One interviews, communication about one's health does not only take place within the healthcare system: parents may have to explain health problems to their children, grown children may have to explain health decisions to their aged parents, friends and siblings disclose health information to one another. There are also a variety of health promotion programs and investigations aimed at understanding health communication at these levels (e.g., Ladapo et al., 2013). Parents are often encouraged to talk to their children about health behaviors such as alcohol consumption and practicing safe sex. This is generally thought to promote better health decision making, especially among adolescents. Given the existing literature regarding interpersonal communication about health topics, it was no surprise that these items emerged as a separate factor.

Participants in Phase One interviews outlined several strategies for determining whether health information was indeed credible. Others also mentioned that the information should come from a source they trust. These findings were expected given previous research in these areas. What was surprising in the current study was that many

of the reverse coded items designed to capture these Credibility Assessments in Phase Two correlated with the discriminant validity concept of Sensation Seeking. It may be that the tendency to check for health information credibility is more of a personality trait (a person is more careful and wants accurate information from an expert) than it is a skill. One can imagine a person capable of examining health information carefully to determine the author's intent for writing the information or comparing the information to other sources to generate a "best" answer. However, choosing to not engage in these credibility checks because they are more willing to take risks or would not have a tendency to worry about their health and the source from which their health information comes, may be more reflective of risk taking. Research often asks participants to make "assessments" about the credibility of content (e.g., Eastin, 2001); however, future research may benefit from observational investigations to determine how likely patients are to make these assessments.

In the present study, the skill of Health Information Seeking Experience emerged as a combination of two hypothesized themes – Knowing When to Search and Finding Health Information Online. Most often, participants in Phase One suggested that they knew they needed to begin a health information search when they encountered a health issue such as getting the flu. In these cases, health information seeking was generated based on the fact that the patient did not have information they needed about attending to or treating their health issue, as outlined in health information seeking frameworks (Griffin, Dunwoody, and Neuwirth, 1999; Afifi & Weiner, 2004). Interestingly, this information discrepancy was not always noted by the individual but could be noted by a

friend, co-worker, or romantic partner. For example, for a patient who had recently developed a large cyst on their wrist, the patient's partner communicated their information discrepancy and resulting anxiety to the patient, who was otherwise unconcerned about the cyst. The partner's information discrepancy and anxiety motivated the patient to look for health information about the cyst on his/her own time, rather than being motivated by their own information discrepancy and anxiety.

Additional research that explores these concepts in greater detail is needed, especially that which examines the intersection between cultivating a personal health context (i.e., understanding what types of health information are relevant and not relevant to you given your personal health history) and finding health information online, "when the Internet has become such a hypochondriacs' playground, where they can discover a multitude of symptoms and immediately start to be frightened by them" (No Author, 2014).

#### **5.4 PROPOSED IMPLICATIONS**

The current study was designed to support the four-facet approach to health literacy serves as a first step toward creating and testing measurement tools for each health literacy facet. As such, this work is highly exploratory in nature. Given this, implications from the results of the present study must be approached with caution prior to conducting a re-test with the remaining survey items. Suggestions for additional research paths that might be interesting given the exploratory findings in the present study include increasing patient skills in each of the factor areas (the main focus of improving health literacy is by improving these skills). Additional work can also be done

within the health system environment to facilitate the health information seeking process for patients.

#### **5.4.1 Improving Patient Skills**

For many of the skills themes/factors identified through the current study, existing literature on these topics suggests that patients can improve these skills as they acquire more experience in that area. For example, finding health information online may become easier the more times a patient performs this activity (given that they have good/beneficial outcomes rather than experiencing frustration or anger). As the patient begins to experience outcomes, such as the type of results given through a specific search engine entry and the new results given with a revision of that entry, they are essentially learning to look for health information online. As such, a patient with experience in a given skill does not “start over” every time they look for health information, they learn from past experience.

It may be that fostering an understanding of one’s own health history and context, and the ability to find health information when it is needed, should be done at a younger age through the classroom. Skills identified in the current study such as being able to find numerical and text information in a variety of documents could easily be incorporated into a classroom setting by giving math and reading assignments that incorporate health topics such as finding the number of calories on a nutrition label. This may be one avenue for improving patient skills for finding health information.

#### **5.4.2 Improving a Patient's Environment**

Interventions that aim to improve patient skills for finding health information could have direct implications for improving health outcomes. In addition to equipping patients with better skills for finding health information, it may be that changes to health information itself could contribute to facilitating the finding of health information.

For example, given the prevalence of use and reliance on health information found online, future research that explores quality control of health information online is needed. In several interviews, participants (mostly health literate patients and health professionals) proposed the introduction of a seal or stamp that could be added to health web pages where information had been verified by a professional. Indeed, digital badges are growing in popularity across online content. An article from U.S. News & World Report describes how online badges can be used in the field of education, where leaders in an online class might be awarded a badge for their high performance, which is then displayed on the individual's comments, posts, and homepage (Friedman, 2014). A similar badge system might be useful for health information, where patients who lack skills for online health information seeking and credibility assessment such as content and source credibility could look for the badge on a health information page (or forum) to identify quality content and sources. Using a badge system over time might teach patients lacking in these skills what a credible health information website looks like and what factors are more common on non-credible sites.



Overall, research that confirms each of the factors identified in the present study is needed. After producing valid and reliable items, more suggestions for future research and implications in these areas can be made.

## **5.5 LIMITATIONS**

Although the present study offers initial insight into the skills that patients and health professionals believe are needed for successfully finding health information, the study is not without its limitations. First, convenience samples, yielding cross-sectional data were used in the present study. As such, the data are limited to the samples included in the study and should not be generalized to the U.S. population as a whole. The Phase Two sample was highly educated, spoke fluent English, and was a majority White. If the sample had included greater demographic variability, generalization to the population of adults in the U.S. would be a greater possibility.

Another limitation of the present study was the length of the survey included in Phase Two. After several iterations of timed testing, the final survey used in the present study took about 30 to 45 minutes to complete. It could be that the length of the survey resulted in participant fatigue, where participants were more likely to skip questions or enter random answers. Given the exploratory nature of this study, it was important for the survey to include items for the hypothesized constructs, which could allow for model trimming. Future iterations of this survey would not require nearly as much time as the survey would be limited to include only the items that performed well.

In addition, the nature of the current study was highly exploratory. This is the first study to identify skills that patients and health professionals believe are needed for

finding health information. Given the exploratory nature of the study, the relationships between the factors uncovered in the present study cannot yet be determined. The survey items developed must be re-tested with another sample to ensure that the items are valid and reliable. With a new sample using the items retained in the present study, confirmatory factor analysis can be performed to establish the relationships between variables. This is standard practice for the development of new measurement tools (e.g., Jordan et al., 2013).

#### **5.6 BENEFITS AND LESSONS LEARNED FROM THE FIRST FOUR-FACET STUDY**

The present study was the first in a series of exploratory and confirmatory work aimed at creating an understanding of and measurement tools for each facet of the four-facet approach to health literacy. This study adapted a mixed-methods design as utilized by Jordan and colleagues (2013) in their development of the Health Literacy Management Scale (HeLMS).

This included interviewing patients and health professionals about the skills they thought were needed for finding health information (Phase One), followed by administering a survey that included items created from the Phase One interview content and themes (Phase Two). As a result, several factors were extracted from the data, which are thought to reflect important skills needed for finding health information.

Based on the current study, the use of this two-phase methodology could certainly be utilized to explore the other facets of health literacy. Several notes emerged in the development and execution of the present study. First, in their development of HeLMS, Jordan and colleagues did not include health professionals in their initial interviews. The

addition of these professionals to the current study was an effort to include this important voice in the conversation about what constitutes the skills needed for finding health information. Health professionals work with patients on a regular basis and are essential players in promoting health literacy and critical health outcomes. It could be that these professionals would offer unique insight not considered by patients. In the current study, health professionals generally exhibited consistency with patients in how they answered many of the Phase One interview items (i.e. they overlapped with health literate patients in the skills they identified as important and overlapped with low health literacy patients in that they were able to identify what a person with low health literacy might do in a given situation where they needed to find health information).

However, in future research, health professionals should continue to be included in Phase One interviews. It may be that health professionals have greater insight in a facet such as “communicating about health information,” in which they engage with the patient directly, rather than perhaps generating more of an educated guess about how patients look for health information (since they are likely not sitting with the patient while they engage in this process). The order in which Phase One interviews were conducted: Low health literate patients, adequate health literate patients, and the health professionals seems to have produced a logical trajectory for theme and code convergence and would be used in future research if possible.

Ideally, for future research the Phase Two survey would be implemented in a more demographically diverse sample. The present study used an online survey to collect quantitative data on items created from Phase One interviews. This sample was highly

educated and mostly White. Future research could aim to amend the Phase Two approach to include patients of limited education or literacy, or translated into Spanish. An online survey could be utilized with these audiences if the items could be audio-recorded and played through headphones. Expanding the demographic variability to match that of the greater U.S. population would allow for increased capacity for the generalization of study results.

The two-phase methodology utilized in the present study exhibited a number of benefits. One includes being able to increase content validity of the Phase Two survey by generating items from examples and language used by participants in Phase One. This may increase the likelihood that participants in Phase Two comprehend the items included on the survey and respond accordingly. Additionally, immersing oneself in the Phase One interviews allows a researcher to become closer to the issues that patients encounter and the frequency with which they face these challenges. In the present study, several themes and factors were extracted through the two phases that were not hypothesized as a result of reviewing available literature.

Given the lessons learned and benefits, it seems that this two-phase approach to understanding and developing a measurement tool for the other three facets of health literacy would be a promising endeavor.

## **5.7 BENEFITS OF THIS HEALTH LITERACY CONCEPTUALIZATION**

In addition to producing a two-phase methodology that could be used to explore the other facets of health literacy, a focus of this piece was to introduce the four-facet approach to health literacy. While not a severe departure from the definition of health

literacy, thinking of this construct as one comprised of four facets yields a number of benefits. It is important to consider the contributions this adds to the fields of health literacy research and practice, as it may be argued that by thinking of health literacy as four separate but related facets, the construct experiences a reduction in parsimony. Parsimony is but one criterion for what constitutes important theoretical contributions (Chaffee & Berger, 1987).

One of the strongest advantages of thinking about health literacy as distinct facets is its contribution to measurement. Each health literacy facet can be measured using either a battery of tasks or self-report items – or a combination of these items. One critical concern for understanding health literacy and its impact on health decisions and outcomes is that the current measures of health literacy do not reflect the definition. Piecing out the facets thought to drive health literacy offers a concrete definition that is matched by corresponding measurements. Additionally, each facet is supported by some existing knowledge and frameworks, which could help build a more stable framework for health literacy.

Thinking of health literacy as a factor comprised of four facets also contributes responses to some of the remaining questions we have about health literacy: 1.) Should health literacy be considered an individual level factor or as something greater?; Is health literacy a clinical concept, or public health, or both? Whose domain is this?; 3.) Is health literacy a fixed construct or can it change over time?

First, we can explore the components of health literacy as individual-level characteristic *and* as features of the healthcare organization. In the same way that the

facets have been addressed for an individual's finding, understanding, using, and communicating about health information, we can also think about the healthcare system as contributing to these separate facets, as suggested in 5.4.2 (Improving a Patient's Environment).

This strategy could similarly be applied across health contexts including clinical, public health, and domain-specific areas (e.g., oral health). In doing this, we would not need to create new conceptualizations and measures for each context (e.g. health literacy means "this" in one context, but "that" in another context) but instead seek to understand how finding, understanding, using, and communicating about health information takes place in these contexts. It would be interesting if future research showed that a patient's capacities for the health literacy facets were better for public health information than they were for clinically driven details (or, across different health topics such as oral health, diabetes, etc.). It is currently assumed that this is not the case – that information in one area of health promotion is not different from others; however, with calls to improve the quality of health information available to consumers, looking at whether patients encounter challenges in health literacy facets across health contexts might point to areas of health that are doing a better job of addressing this issue. Looking at differences across contexts could shed light on the features of that context that put barriers in place for the health literacy facets.

Also, thinking about health literacy as separate facets could contribute substantial changes to what we know about this concept over time. Is health literacy static or dynamic? We can only know with more research in this area. Using the four facets of

health literacy, we have distinct areas for which we can examine over time. By capturing health literacy just once and with measures that only reflect literacy and numeracy (which, Berkman, Davis, and McCormack, [2010] argue do not change over time without intervention) as we currently do, we substantially limit our ability to look at how health literacy changes, if at all. Similarly, the health literacy facets offer specific areas for intervention, which, if effective interventions are created, would promote individual efforts of each health literacy component, and result in an overall improvement in health literacy.

If we were to gather all of the conceptualizations and definitions of health literacy throughout the years and rate them using Chaffee and Berger's (1987) criteria for "good theory," the conceptualization of health literacy as being comprised of four facets would receive point deductions in the area of parsimony (because the concept moved from one piece to four). However, given the benefits of clear measurement opportunities, this conceptualization gains points in several other areas outlined by these authors including explanatory power – through the four facets we may be able to explain the occurrence of low health literacy, pointing to very specific areas in which improvement is needed; predictive power – we may now get one step closer to looking at the specific mechanisms that drive health literacy to cause health outcomes, if at all; internal consistency – it makes sense to think of the health literacy components as separate factors that contribute to a health literacy umbrella, in doing this, it is also easier to point to what health literacy "is" rather than trying to explain this latent factor without concrete pieces; heuristic provacativeness – through facet assessments we may be able to replicate findings over

time, thus contributing to a greater knowledge of health literacy and health; and organizing power – we may finally be able to organize the existing literature on health literacy – where it seems that there is currently great confusion about what health literacy is and is not (Chaffee & Berger, 1987). Although there are thoughts about how the act of piecing out the health literacy facets might impact the overall understanding and usability of the concept given increased parsimony, it is clear that this exchange is happily made given the numerous benefits of thinking about health literacy in this way.

One complication that makes the current conceptualization of health literacy a challenge for application in research is that, if health literacy is thought to incorporate finding, understanding, using, and communicating about health information (by definition), then health literacy should not be used as a predictor of one's ability to perform any of these tasks separately. In this way, if health literacy is thought to be a composite of four variables, using the composite to predict an individual outcome should encounter problems with multicollinearity. Studies that find health literacy to be a better predictor of a health literacy component than other factors such as education (e.g. Lindau et al., 2002) may only be finding these associations given this confusion. From one article, "health literacy may influence information seeking" (Shieh, Mays, McDaniel, & Yu, 2009, p972); indeed, information seeking is part of health literacy. Similarly, "health literacy was independently related to disease knowledge" (Gazmararian, Williams, Peel, & Baker, 2003, p267). Again, yes this should be the case if health literacy includes a facet of "understanding" health information. There is a host of studies suggesting that



health literacy predicts knowledge of specific health topics (Mosher et al., 2012; Osborn et al., 2011; Peterson et al., 2007).

## **5.8 FUTURE RESEARCH**

In addition to conducting a confirmatory factor analysis using the Phase Two items retained in the current study, there are several paths for future research given the results from the present study. First, it is clear that the “finding health information” facet of health literacy likely requires a unique set of skills, which perhaps differ from the skills needed for the other health literacy facets. Future research can use the present study as a model for developing measurement tools for the other health literacy facets. Appendix A exhibits the four factor/facet model of health literacy, which is the first to point to the mechanisms that drive the concept of health literacy, rather than viewing this critical concept as either an independent or dependent variable. It is this understanding of the factors that comprise health literacy that will allow future research to generate interventions aimed at improving these four skill sets, and ultimately lead to better health outcomes for patients. It would be advantageous for future research to pool findings from the present study with Jordan et al. (2013) to determine the initial concepts that are thought to drive the other health literacy factors.

In addition to future research studies that contribute directly to better understanding the concept of health literacy, each of the factors extracted in the present study present a unique avenue for future research. For example, more research is needed about what constitutes best practices for designing health information in an effort to help patients find (and subsequently understand, use, and communicate about) these important

details. Findings from the current study suggest that different types of health texts such as labels, paragraphs, and perhaps challenging vocabulary or medical jargon may warrant different skills for finding information within each of these documents. Houts and colleagues (2006) suggest that health information should incorporate text and pictures in an effort to help patients engage with this content. Other work that offers suggestions to those who design health materials could save important resources and perhaps reduce negative health outcomes.

## **5.9 CONCLUSION**

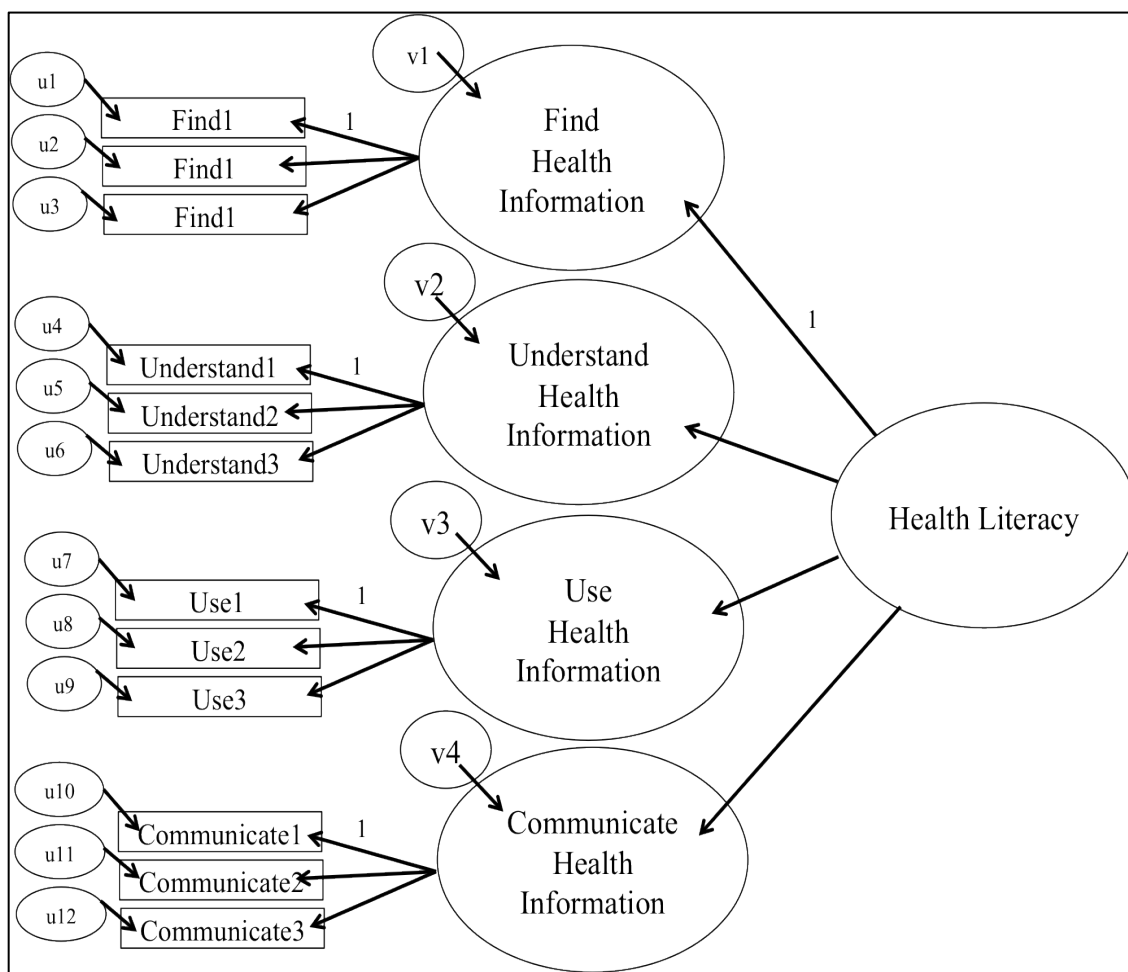
Improving patient skills for finding health information is an important first step to increasing the prevalence of adequate health literacy in the U.S. Progressing patient health literacy skills can have beneficial health implications that traverse health outcomes including getting cancer screenings, adhering to prescription medication instructions, and fewer trips to the emergency room (Berkman et al., 2011), and overall better health (IOM, 2009; Nielsen-Bohlman et al., 2004). As such, a focus on improving the facets of health literacy through intervention could yield more global benefits than a specific emphasis aimed at improving skills within the context of a specific health outcome (e.g., diabetes or oral health). Additionally, focusing on health literacy, an “upstream” factor in determining health could save time and money when creating health promotion interventions.

A central aim of this paper was to introduce the four-facet approach to defining, conceptualizing, and measuring health literacy. Although this is not a “new” concept as it draws directly from the Berkman, Davis, and McCormack (2010) definition of health

literacy, the present piece is the first to create a model that focuses on the mechanisms that drive health literacy. Results from the present study suggest that individuals may utilize a collection of skills to find health information, each of which might be employed depending on the type of health information source. Future research is needed regarding the other three facets of health literacy to establish a full measurement tool for health literacy. In order for health literacy interventions to be developed, researchers and health practitioners must first agree on a definition, conceptualization, and measurement of health literacy. The ideas presented in this paper reflect one avenue for streamlining this important body of work.

## Appendix A: Conceptualizing Health Literacy

It is possible to think of health literacy as a latent construction made up of four distinct components: finding, understanding, using, and communicating about health information. In this measurable model, items thought to reflect each of the components could be observed. One could then determine which of the health literacy components provides the greatest contribution to the overall concept of health literacy – which component is responsible for driving this factor, or are all of the components equal in their contribution? Important confounding variables could be controlled in analyses, such as race/ethnicity, education, and age.



## **Appendix B: Phase One Qualitative Interview Scripts**

NOTE: Reflections during data collection that contributed to revisions in the interview scripts are noted using parentheses with Cambria, italics font: *(Like this)*

### **1.) Initial Interview Script for Patients:**

#### Step 1: Consent Form

Today we are going to talk about how people find health information. The purpose of this project is only to better understand this process and the skills that are needed for this activity. First, do you have any questions for me before moving into this interview? I want to remind you that your answers will never be tied to your name or where you work. We will keep your information completely confidential as stated in the consent form. Please just say “skip” if you’d like me to skip a question, you are not obligated to answer any question you are uncomfortable with answering. You may leave this study at any time and your decision to leave will not impact your relationship with the University of Texas in any way.

#### AUDIO RECORDING WILL BEGIN HERE.

#### Step 2: What is the process of finding information in “General”?

Today I’d like to talk to you about how people find health information – but I want to start by first talking about how people find information in general.

So, to start, could you describe for me the last time you looked for some information that wasn’t about health – this could be something such as looking up how to get to a certain location or finding information about upcoming events.  
(Think of a friend and describe what they did in this situation)

You talked about (event the participant described) – I’m wondering, what are some things a person needs to be good at to be able to do what you did?

#### Step 3: The Process of Finding Health Information

Great, so we’ve been talking about how people find information in general, now let’s talk about how people do this process when they are looking for health information specifically.

Can you describe a time for me in which you found some information about a health topic?

(Think about the last time you did this)

(What was the information, where did they go, what was the process like?)

(Think about a friend or family member and how they did this)

(Give examples of health information seeking such as – I went to my doctor to ask them about a new medication, I looked online to read about the flu, I asked my friend about what she takes to prevent allergies)

What was difficult about this process for you? Did you struggle or feel frustrated at any point?

(Did you ask anyone for help with this?)

Were there any parts of this process that were easy for you?

If you were going to give advice to someone about how they could find information on a health topic, what would you tell them?

What kinds of skills should this person have in order to find the information?

How does this process compare to the one you described earlier (for general information)? Are there any skills that someone might need to find health information specifically, rather than information in general?

#### Step 4: Does this Process Differ across Health Topics?

So far we've talked about the general process of finding health information.

What kinds of health topics (other than the one(s) you mentioned above) have you looked for in the past?

(After participant mentions topics) – What do you think about these different health topics – are some easier or more difficult to find information about? (If so, which topics are easy/difficult)?

What do you think makes these topics hard to get information about?

What are some skills that could help you get better at finding health information about this topic?

#### Step 5: Does this Process Differ across Media Platforms?

Also, it seems like people can find health information a lot of different places – could you tell me about some different places you've looked for health information?

If someone was going to look for health information in (MEDIUM), would they need any special skills to find information in (MEDIUM)?

Is there a particular place that you go for health information most often?  
What about the (MEDIUM) helps you to get information?

AUDIO RECORDING WILL END HERE

Step 6: Demographics

(Researcher will ask orally)

What is your gender?  
Could you provide me with your race and ethnicity?  
How old are you?  
What is your current occupation?

Step 7: Newest Vital Sign (for “patients” sample only)

**2.) Revised Interview Script for Patients, Updated After First Day of Data Collection at GED Attainment Center:**

**(Step 1 Consent identical to initial script)**

Step 2: What is the process of finding information in “General”?

Today I’d like to talk to you about how people find health information – but I want to start by first talking about how people find information in general.

So, to start, could you describe for me the last time you looked for some information that wasn’t about health – this could be something such as looking up how to get to a certain location or finding information about upcoming events.

(Think of a friend and describe what they did in this situation)

You talked about (event the participant described) – I’m wondering, what are some things a person needs to be good at to be able to do what you did? *(not surprisingly, asking people to list skills doesn’t get much of a response – I’m re-wording this with the hopes that people will have a better understanding of what I’m asking)*

You found this information with ease – what are some challenges that someone else might have in finding the same information you did. *(Adding this question to get the other side of the information – they did this successfully (and usually, the information*

*they were looking for was really straightforward so they didn't have any problems) – I want to see if they think other people would have these problems to potentially shed light on any barriers to this information seeking without having the participant admit that they encountered any barriers.)*

### Step 3: The Process of Finding Health Information

Great, so we've been talking about how people find information in general, now let's talk about how people do this process when they are looking for health information specifically.

Tell me a little bit about any health information you've learned recently – it can be on any topic. Anything you found interesting or that surprised you.

*(For the different examples given) – how did you learn about this health information? (Here, I'm interested to see if that seeking VS. incidental learning comes out at all? I want to give people the opportunity to give examples that aren't just about active seeking if possible?)*

Have you had any health problems come up recently that made you want to look for health information? *(I want to make sure I delve into what motivates the search so I can start asking about the process of info seeking starting there. It seems that participants in this group start looking for information when they experience a health problem.)*

*(This could be about themselves, a parent, a child, etc.)*

*(This could also be about their friend – did a friend go through something recently?)*

Walk me through the specific steps you took to find that information.

*(Think about the last time you did this)*

*(What was the information, where did they go, what was the process like?)*

*(Think about a friend or family member and how they did this)*

*(Give examples of health information seeking such as – I went to my doctor to ask them about a new medication, I looked online to read about the flu, I asked my friend about what she takes to prevent allergies)*

What was difficult about this process for you? Did you struggle or feel frustrated at any point?

*(Did you ask anyone for help with this?)*

How did it make you feel while you were looking for the information? *(To dive deeper into themes of frustration or other emotions while seeking that information and then, if any, feelings after the seeking is over.)*



Were there any parts of this process that were easy for you?

How did you feel after you found the information you were looking for?

If you were going to give advice to someone about how they could find information on a health topic, what would you tell them?

What kinds of skills should this person have in order to find the information?

How does this process compare to the one you described earlier (for general information)? Are there any skills that someone might need to find health information specifically, rather than information in general?

Have you ever been reading or doing something else when you accidentally came across some health information – maybe reading a newspaper and there was an article you were surprised to read? *(Again, to give an opportunity to mention something that happened incidentally – some participants tell me that they play around on the Internet or read newspapers casually – here’s a chance to mention anything they ran into without intent.)*

Have you ever NOT found information you were looking for?

#### Step 4: Does this Process Differ across Health Topics?

So far we’ve talked about the general process of finding health information.

What kinds of health topics (other than the one(s) you mentioned above) have you looked for in the past?

(After participant mentions topics) – What do you think about these different health topics – are some easier or more difficult to find information about? (If so, which topics are easy/difficult)?

What do you think makes these topics hard to get information about?

What are some skills that could help you get better at finding health information about this topic?

#### Step 5: Does this Process Differ across Media Platforms?

Also, it seems like people can find health information a lot of different places – could you tell me about some different places you’ve looked for health information?

If someone was going to look for health information in (MEDIUM), would they need any special skills to find information in (MEDIUM)?

Is there a particular place that you go for health information most often?  
What about the (MEDIUM) helps you to get information?

**(Step 6 [Demographics] and Step 7 [Newest Vital Sign] identical to initial script)**

**3.) Revised Interview Script for Patients, Updated After Second Day of Data Collection at GED Attainment Center:**

Step 2: What is the process of finding information in “General”?

Today I’d like to talk to you about how people find health information – but I want to start by first talking about how people find information in general.

What is the definition of finding information – what does that mean to you? *(Maybe this is needed to get everyone on the same page – worth a shot )*

So, to start, could you describe for me the last time you looked for some information that wasn’t about health – this could be something such as looking up how to get to a certain location or finding information about upcoming events.  
(Think of a friend and describe what they did in this situation)

You talked about (event the participant described) – I’m wondering, what are some things a person needs to be good at to be able to do what you did?

You found this information with ease – what are some challenges that someone else might have in finding the same information you did.

Step 3: The Process of Finding Health Information

Great, so we’ve been talking about how people find information in general, now let’s talk about how people do this process when they are looking for health information specifically.

Tell me a little bit about any health information you’ve learned recently – it can be on any topic. Anything you found interesting or that surprised you.

(For the different examples given) – how did you learn about this health information?

Have you (or a friend or family member) had any health problems come up recently that made you (or them) want to look for health information?

(This could be about themselves, a parent, a child, etc.)

(This could also be about their friend – did a friend go through something recently?)

Walk me through the specific steps you took to find that information.

(Think about the last time you did this)

(What was the information, where did they go, what was the process like?)

(Think about a friend or family member and how they did this)

(Give examples of health information seeking such as – I went to my doctor to ask them about a new medication, I looked online to read about the flu, I asked my friend about what she takes to prevent allergies)

What was difficult about this process for you? Did you struggle or feel frustrated at any point?

(Did you ask anyone for help with this?)

How did it make you feel while you were looking for the information?

Were there any parts of this process that were easy for you?

How did you feel after you found the information you were looking for?

Tell me about anything that you WOULDN'T want to do while looking for health information, is there anything that's a bad idea? Or mistakes someone might make? *(Finding health information seems to be really easy for everyone (so they say) – I'm wondering what they think would be like, oh, whoops – that's not getting me to where I need to be.)*

What does someone who is good at finding health information look like?

What does someone who is bad at finding health information look like?

How does this process compare to the one you described earlier (for general information)? Are there any skills that someone might need to find health information specifically, rather than information in general? *(I decided this question was kind of worthless – if they ran into some health information, I'd rather hear about that organically)*

What are some places you've seen health information where you didn't expect it – are there any places you'd want to put any health information?

Have you ever NOT found information you were looking for?

Has the process of health information seeking changed over time? Why/Why not?

(What is the future of health information seeking, if you had to guess) (*A lot of folks hit on the Internet, but what is the future for this behavior, is anything going to come along to make this process easier? Different?*)

Why is finding health information important? What are some of the benefits? (*Again, it seems like people think that finding health information is really easy and that all of you have to do is ask anyone and you will get the information you need. Here I'm trying to get at the motivation behind this process a little more – how do you know when it's time?*)

(How do you know when it's time to look for health information?)

Are there any downsides to finding this information?

Is there such a thing as “good” health information and “bad” health information? What's the difference between finding information and finding “good” information. (*Is there a difference here? I want to get a little bit more at how health information credibility or quality is evaluated , if at all.*)

Step 4: Does this Process Differ across Health Topics?

So far we've talked about the general process of finding health information.

What kinds of health topics (other than the one(s) you mentioned above) have you looked for in the past?

(After participant mentions topics) – What do you think about these different health topics – are some easier or more difficult to find information about? (If so, which topics are easy/difficult)?

What do you think makes these topics hard to get information about?

What are some skills that could help you get better at finding health information about this topic?

Step 5: Does this Process Differ across Media Platforms?

Also, it seems like people can find health information a lot of different places – could you tell me about some different places you've looked for health information?

If someone was going to look for health information in (MEDIUM), would they need any special skills to find information in (MEDIUM)?

Is there a particular place that you go for health information most often?\*\*\* (make sure to hit this one) *(a theme that is emerging seems to be that some go out of their way to ask people about health topics – they might ask ANYONE whereas others seem to prefer individual info seeking, such as using the Internet )*

(Maybe if they ask someone else, how does that person react?)

What about the (MEDIUM) helps you to get information?\*\*\*

If you were going to give advice to someone about how they could find information on a health topic, what would you tell them?

What kinds of skills should this person have in order to find the information?

#### **4.) Revised Interview Script for Patients, Updated After Third (and final) Day of Data Collection at GED Attainment Center:**

##### Step 2: What is the process of finding information in “General”?

Today I’d like to talk to you about how people find health information – but I want to start by first talking about how people find information in general.

What is the definition of finding information – what does that mean to you?

So, to start, could you describe for me the last time you looked for some information that wasn’t about health – this could be something such as looking up how to get to a certain location or finding information about upcoming events.

(Think of a friend and describe what they did in this situation)

You talked about (event the participant described) – I’m wondering, what are some things a person needs to be good at to be able to do what you did?

You found this information with ease – what are some challenges that someone else might have in finding the same information you did.

##### Step 3: The Process of Finding Health Information

Great, so we’ve been talking about how people find information in general, now let’s talk about how people do this process when they are looking for health information specifically.

Tell me a little bit about any health information you’ve learned recently – it can be on any topic. Anything you found interesting or that surprised you.

(For the different examples given) – how did you learn about this health information?

Have you (or a friend or family member) had any health problems come up recently that made you (or them) want to look for health information? (*Why might someone look for health information?*)

(This could be about themselves, a parent, a child, etc.)

(This could also be about their friend – did a friend go through something recently?)

Walk me through the specific steps you took to find that information.

(Think about the last time you did this)

(What was the information, where did they go, what was the process like?)

(Think about a friend or family member and how they did this)

(Give examples of health information seeking such as – I went to my doctor to ask them about a new medication, I looked online to read about the flu, I asked my friend about what she takes to prevent allergies)

Which of these things do you think comes first – a person’s desire to find health information or good health of a person – does finding health information make someone more healthy or do healthy people search more for information? (*This seems to be an emerging theme in the first few interviews*)

What’s the difference between “looking for” health information and “finding” health information? (*Another attempt to separate – or get different information on the process and the goal.*)

What was difficult about this process for you? Did you struggle or feel frustrated at any point?

(Did you ask anyone for help with this?)

How did it make you feel while you were looking for the information?

Were there any parts of this process that were easy for you?

How did you feel after you found the information you were looking for?

Tell me about anything that you WOULDN’T want to do while looking for health information, is there anything that’s a bad idea? Or mistakes someone might make?

What are your strategies for finding health information? (*this will give participants an opportunity to talk about how they go about doing this – any specific details/suggestions*)

What does someone who is good at finding health information look like?

What does it mean to be good at finding health information?  
What does someone who is bad at finding health information look like?  
What does it mean to be bad at finding health information?  
How does this process compare to the one you described earlier (for general information)? Are there any skills that someone might need to find health information specifically, rather than information in general?

What are some places you've seen health information where you didn't expect it – are there any places you'd want to put any health information?  
Have you ever NOT found information you were looking for?

Has the process of health information seeking changed over time? Why/Why not?  
(What is the future of health information seeking, if you had to guess)  
Why is finding health information important? What are some of the benefits?

(How do you know when it's time to look for health information?)

Are there any downsides to finding this information?

Is there such a thing as “good” health information and “bad” health information?  
What's the difference between finding information and finding “good” information.  
Step 4: Does this Process Differ across Health Topics?

So far we've talked about the general process of finding health information.

What kinds of health topics (other than the one(s) you mentioned above) have you looked for in the past?

(After participant mentions topics) – What do you think about these different health topics – are some easier or more difficult to find information about? (If so, which topics are easy/difficult)?

What do you think makes these topics hard to get information about?

What are some skills that could help you get better at finding health information about this topic?

Step 5: Does this Process Differ across Media Platforms?

Also, it seems like people can find health information a lot of different places – could you tell me about some different places you've looked for health information?

If someone was going to look for health information in (MEDIUM), would they need any special skills to find information in (MEDIUM)?

Is there a particular place that you go for health information most often?\*\*\* (make sure to hit this one)

(Maybe if they ask someone else, how does that person react?)

What about the (MEDIUM) helps you to get information?\*\*\*

If you were going to give advice to someone about how they could find information on a health topic, what would you tell them?

What kinds of skills should this person have in order to find the information?

If you were given a pamphlet about health information, or you were looking online for this information, how can you tell what's important? How can you tell what is credible? What steps do you take to know that the information is credible? *(This is something I haven't gotten much about yet – how do you extract the important information – this kind of goes along with how do you know when you're done?)*

## **1.) Initial Interview Script for Health Professionals:**

### Step 1: Consent Form (see separate document)

Today we are going to talk about how people find health information. The purpose of this project is only to better understand this process and the skills that are needed for this activity. I will be asking you questions about how you find health information for yourself and family but I will also be asking you questions about how you see patients experience the process of finding health information.

First, do you have any questions for me before moving into this interview? I want to remind you that your answers will never be tied to your name or where you work. We will keep your information completely confidential as stated in the consent form. Please just say “skip” if you'd like me to skip a question, you are not obligated to answer any question you are uncomfortable with answering. You may leave this study at any time and your decision to leave will not impact your relationship with the University of Texas in any way.

### AUDIO RECORDING WILL BEGIN HERE.

### Step 2: What is the process of finding information in “General”?



Today I'd like to talk to you about how people find health information – but I want to start by first talking about how people find information in general.

So, to start, could you describe for me the last time you looked for some information that wasn't about health – this could be something such as looking up how to get to a certain location or finding information about upcoming events.  
(Think of a friend and describe what they did in this situation)

You talked about (event the participant described) – I'm wondering, what types of skills do you think a person needs to find that information?

### Step 3: The Process of Finding Health Information

Great, so we've been talking about how people find information in general, now let's talk about how people do this process when they are looking for health information specifically.

Can you describe a time for me in which you found some information about a health topic?

(Think about the last time you did this)  
(What was the information, where did they go, what was the process like?)  
(Think about a friend or family member and how they did this)

Do you think the process of finding health information differs between patients with adequate and less than adequate health literacy? (Why/Why not?)

Can you describe what this process might be like for someone who has low health literacy?

What are some of the skills you think your patients need for this process?

What are your patients already good at?

What are some skills they might lack (or need improvement)?

### Step 4: Does this Process Differ across Health Topics?

So far we've talked about the general process of finding health information.

Do you think about health topics differ at all in how challenging it is to find information on the topic – are some easier or more difficult to find information about?  
(If so, which topics are easy/difficult)?

What do you think makes these topics hard to get information about?

What are some skills that could help you get better at finding health information about this topic?

Step 5: Does this Process Differ across Media Platforms?

Also, it seems like people can find health information a lot of different places – could you tell me about some different places that patients tend to go for health information?

What kind of correlation, if any, do you think there is between health topic and the place (medium) in which a patient looks for information? For example, do more people tend to go online for information about cancer than they do for information about the flu?

If someone was going to look for health information in (MEDIUM), would they need any special skills to find information in (MEDIUM)?

Is there a particular place that you go for health information most often?  
What about the (MEDIUM) helps you to get information?

AUDIO RECORDING WILL END HERE

Step 6: Demographics

(Researcher will ask orally)

What is your gender?

Could you provide me with your race and ethnicity?

How old are you?

What is your current occupation?

## **2.) Revised Interview Script for Health Professionals:**

### Step 2: What is the process of finding information in “General”?

What does it mean to you to “find” information?

Today I’d like to talk to you about how people find health information – but I want to start by first talking about how people find information in general.

So, to start, could you describe for me the last time you looked for some information (in general)– this could be something such as looking up how to get to a certain location or finding information about upcoming events.

(Think of a friend and describe what they did in this situation)

You talked about (event the participant described) – I’m wondering, what types of skills do you think a person needs to find that information?

### Step 3: The Process of Finding Health Information

Now we will switch over to a health context.

Can you talk to me about some reasons why someone might look for information about health topics?

Also, what are some reasons why someone might not look for health information?

Can you describe a time for me in which you found some information about a health topic?

(Think about the last time you did this)

(What was the information, where did they go, what was the process like?)

(Think about a friend or family member and how they did this)

Can you describe what this process might be like for someone who has low health literacy? Do you think the process of finding health information differs between patients with adequate and less than adequate health literacy? (Why/Why not?)

What are some of the skills you think your patients need for this process?

What are your patients already good at?

What are some skills they might lack (or need improvement)?

Step 4: Does this Process Differ across Health Topics?

So far we've talked about the general process of finding health information.

Do you think about health topics differ at all in how challenging it is to find information on the topic – are some easier or more difficult to find information about?  
(If so, which topics are easy/difficult)?

What do you think makes these topics hard to get information about?

What are some skills that could help you get better at finding health information about this topic?

Step 5: Does this Process Differ across Media Platforms? *(Ask this question directly)*

Also, it seems like people can find health information a lot of different places – could you tell me about some different places that patients tend to go for health information?

What kind of correlation, if any, do you think there is between health topic and the place (medium) in which a patient looks for information? For example, do more people tend to go online for information about cancer than they do for information about the flu?

If someone was going to look for health information in (MEDIUM), would they need any special skills to find information in (MEDIUM)?

Is there a particular place that you go for health information most often? *(Ask if this has not already been answered)*

What about the (MEDIUM) helps you to get information?

## Appendix C: Phase Two Self-Report Survey Items

The items and descriptive statistics used for the final exploratory factor analysis are included below.

If you were looking for TEXT-based information related to your health (rather than numbers-based information like quantities), please rate the level of difficulty you would have with finding that information in each of the following printed materials: (Examples of text-based information related to health include looking at ingredients listed on a nutrition label or directions for taking a medication.

<b>Label</b>	<b>Item</b>	<b>M</b>	<b>SD</b>	<b>Skew</b>	<b>Kurtosis</b>
Q1_1	A medical bill	4.66	1.78	-0.397	-0.760
Q1_2	A story in a newspaper	5.28	1.51	-0.691	-0.116
Q1_3	An over-the-counter medication label	5.38	1.35	-0.643	-0.100
Q1_5	A graph or chart	5.05	1.54	-0.603	-0.204
Q1_6	Instructions that occur in paragraphs	5.42	1.35	-0.521	-0.458
Q1_8	The fine print on a drug advertisement	4.61	1.68	-0.154	-1.027
Q1_10	A research article	5.02	1.44	-0.328	-0.620
Q1_13	A nutrition label	5.44	1.38	-0.695	0.006
Q1_15	A chart that lists your health insurance benefits	4.85	1.68	-0.461	-0.631
Q1_16	A magazine article	5.45	1.39	-0.726	-0.099
Q1_18	Information from a textbook	5.32	1.4	-0.533	-0.297
Q1_19	A pamphlet with key points about health	5.62	1.33	-0.896	0.512

We will now ask you to rate the level of difficulty you would have with finding health information in these printed materials if you were looking for NUMBERS-based information, rather than text-based information: (Examples of numbers-based information related to health include looking at the number of calories listed on a nutrition label or the appropriate quantity of a medication to take.

<b>Label</b>	<b>Item</b>	<b>M</b>	<b>SD</b>	<b>Skew</b>	<b>Kurtosis</b>
Q4_1	A medical bill	4.93	1.8	-0.655	-0.493
Q4_2	A story in a newspaper	5.1	1.6	-0.586	-0.316
Q4_3	An over-the-counter medication label	5.48	1.33	-0.632	-0.106
Q4_5	A graph or chart	5.35	1.31	-0.565	-0.056
Q4_6	Instructions that occur in paragraphs	5.15	1.45	-0.460	-0.553
Q4_8	The fine print on a drug advertisement	4.44	1.7	-0.054	-1.016
Q4_10	A research article	4.89	1.51	-0.283	-0.760
Q4_13	A nutrition label	5.60	1.24	-0.639	-0.149
Q4_15	A chart that lists your health insurance benefits	4.95	1.56	-0.569	-0.320
Q4_16	A magazine article	5.22	1.52	-0.657	-0.146

Q4_18	Information from a textbook	5.19	1.43	-0.499	-0.361
Q4_19	A pamphlet with key points about health	5.52	1.29	-0.829	0.627

Please rate THE FREQUENCY for which you would do the following activities if you were looking for information about a health topic.

<b>Label</b>	<b>Item</b>	<b>M</b>	<b>SD</b>	<b>Skew</b>	<b>Kurtosis</b>
Q8_2	Consider the author's goals/objectives for posting the information.	3.48	1.07	-0.402	-0.342
Q8_3	Check to see if the information is complete/comprehensive.	3.81	0.95	-0.639	0.203
Q8_7	Seek out other sources to validate the information.	4.01	0.94	-0.730	0.047
Q8_10	Verify the author's qualifications or credentials.	3.47	1.14	-0.278	-0.777
Q8_11	Consider whether the information is trying to sell me something.	4.04	0.92	-0.629	-0.317
Q8_14R	Trust that printed information is true.	3.00	1.03	0.108	-0.307
Q8_15R	Use websites ending in .com.	2.49	0.95	0.512	0.263
Q8_16R	Verify the information against things I've heard from my friends or family.	2.5	0.96	0.561	0.228
Q8_19R	Stick with the first thing I read.	3.75	1.01	-0.655	-0.009
Q8_20R	Feel confident that health information generally come from a credible source.	2.96	1.02	0.188	-0.324

Now, please indicate the LEVEL TO WHICH YOU AGREE OR DISAGREE with the following statements:

<b>Label</b>	<b>Item</b>	<b>M</b>	<b>SD</b>	<b>Skew</b>	<b>Kurtosis</b>
Q9_1	I know how to find helpful health resources on the Internet.	5.64	1.225	-0.917	0.863
Q9_21R	When looking for health information online, I feel bombarded with too much information.	5.64	1.23	0.301	-0.416

Q9_7	I feel like I spend an appropriate amount of time looking for health information online.	3.67	1.54	-0.61	0.271
Q9_8	I feel confident in my ability to find health information using the Internet.	5.03	1.37	-0.7	0.006
Q9_22R	Finding health information is more difficult for me than finding health information from other places.	5.58	1.21	-0.553	-0.422
Q9_25R	When looking for health information online I typically start at the top of a search list and work my way down the list until I find what I need.	Bad Item	Bad Item	Bad Item	Bad Item
Q9_10	I can use online search strategies such as quotes and dashes to narrow my searches for health information.	3.11	1.52	-0.561	0.021
Q9_11R	In general, I have a hard time using online search engines to find health information.	5.02	1.44	-0.749	-0.283

The next few statements ask you about finding your way in your environment. Please indicate the LEVEL TO WHICH YOU AGREE OR DISAGREE with the following statements:

Label	Item	M	SD	Skew	Kurtosis
Q10_1	I am very good at giving directions.	5.17	1.39	-0.713	0.260
Q10_4	My sense of direction is very good.	5.15	1.55	-0.728	-0.007
10_14R	I usually let someone else do the navigational planning for long trips.	4.29	1.82	-0.208	-0.890
10_9	I am very good at reading maps.	5.24	1.58	-0.929	0.385

10_10R	I don't remember routes very well while riding as a passenger in a car.	4.14	1.78	0.071	-1.070
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In general, if you were having a conversation with another person about health, please rate the level of difficulty you would have with the following:

<b>Label</b>	<b>Item</b>	<b>M</b>	<b>SD</b>	<b>Skew</b>	<b>Kurtosis</b>
Q115_1	Listening to them and extracting information from the conversation.	6.15	1.58	-0.720	-0.312
Q115_3	Asking questions about a health topic.	6.39	1.50	-0.846	-0.260
Q115_5	Asking them to explain a health-related word you didn't understand.	6.38	1.54	-0.867	-0.275
Q115_6	Talking about symptoms you've experienced (either personally or seen in someone else).	6.26	1.63	-0.836	-0.326
Q115_8	Determining what information in the conversation is relevant to you.	6.30	1.51	-0.767	-0.468
Q115_12	Following along in the conversation.	6.41	1.51	-0.794	-0.506
Q115_10	Responding to what the other person is saying about health.	6.36	1.54	-0.794	-0.471
Q115_11	Asking about symptoms that might be related to a serious health condition.	6.28	1.63	-0.752	-0.624



Q115_7	If you weren't already talking about health, your ability to bring up the topic of health in general.	5.95	1.76	-0.545	-0.798
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Please indicate the LEVEL TO WHICH YOU AGREE OR DISAGREE with the following statements:

<b>Label</b>	<b>Item</b>	<b>M</b>	<b>SD</b>	<b>Skew</b>	<b>Kurtosis</b>
Q11_1	When I read information about a health topic, I am able to tell whether or not the information applies to me.	5.48	1.16	-0.870	1.027
Q11_3	I understand my health history.	5.85	1.05	-0.805	0.369
Q11_5	I know when to look for health information.	5.69	1.14	-0.840	0.649
Q11_10	I feel comfortable making educated guesses about my own health.	5.14	1.43	-0.721	0.117
Q11_15R	When reading about some information about an illness or disease, I would think that I might have that illness or disease, regardless of other factors.	4.58	1.77	-0.334	-0.834
Q11_17R	I would not try to figure out more about an illness I was experiencing.	4.88	1.85	-0.579	-0.762
Q11_20R	I already know how to take care of myself. Looking for health information would be a waste of my time.	5.01	1.73	-0.576	-0.621

Please indicate the extent to which each of the following statements describes you:

<b>Label</b>	<b>Item</b>	<b>M</b>	<b>SD</b>	<b>Skew</b>	<b>Kurtosis</b>
Q15_19	I like to have new and exciting experiences and sensations even if they are a little frightening.	2.64	0.8	-0.278	-0.309
Q15_20	I like doing things just for the thrill of it.	2.57	0.85	-0.222	-0.538
Q15_24	I sometimes like to do things that are a little frightening.	2.5	0.86	-0.159	-0.565
Q15_21	I'll try anything once.	2.58	0.85	0.063	-0.856
Q15_22	I sometimes do 'crazy' things just for fun.	2.37	0.92	0.563	-0.789
Q15_23	I like wild and uninhibited parties.	1.92	0.92	-0.096	-0.645

## Appendix D: Phase Two Survey Demographics

	<b>M (SD)</b>
<b>Age</b>	41.96 (16.36)
<b>Times visited ER in past year</b>	0.50 (1.66)
<b>Times visited health professional in past year</b>	4.84 (6.80)
	<b>n (%)</b>
<b>Gender</b>	
Female	190 (57.4)
<b>Hispanic Ethnicity</b>	
Yes	56 (16.9)
<b>Race</b>	
White	241 (72.8)
African American	58 (17.5)
Asian	14 (4.2)
American Indian, Alaskan Native	4 (1.2)
Other	12 (3.6)
<b>Education</b>	
Less than 8 years	1 (0.3)
8 through 11 years	4 (1.2)
12 years or completed HS	37 (11.2)
Post high school training other than college	8 (2.4)
Some college	93 (28.1)
College graduate	123 (37.2)
Post college	62 (18.7)
<b>Speaks English</b>	
Very Well	307 (92.7)
<b>Has Health Insurance</b>	
Yes	285 (86.1)

## **Appendix E: Phase Two Survey Items Removed From Analysis**

### **1.) Poorly worded item:**

Q9\_25R: When looking for health information online I typically start at the top of a search list and work my way down the list until I find what I need.

### **2.) Items having a majority of non-significant correlations with other items included (first round):**

Q15\_19: I like to have new and exciting experiences and sensations even if they are a little frightening.

Q15\_20: I like doing things just for the thrill of it.

Q15\_24: I sometimes like to do things that are a little frightening.

Q15\_21: I'll try anything once.

Q15\_22: I sometimes do 'crazy' things just for fun.

Q15\_23: I like wild and uninhibited parties.

Q9\_21R: When looking for health information online, I feel bombarded with too much information.

Q10\_14R: I usually let someone else do the navigational planning for long trips.

Q10\_10R: I don't remember routes very well while riding as a passenger in a car.

### **3.) Items having a majority of non-significant correlations with other items included (second round):**

Q8\_19R: Stick with the first thing I read.

Q8\_20R: Feel confident that health information generally comes from a credible source.

Q11\_15R: When reading about some information about an illness or disease, I would think that I might have that illness or disease, regardless of other factors.

Q11\_17R: I would not try to figure out more about an illness I was experiencing.

Q11\_20R: I already know how to take care of myself. Looking for health information would be a waste of my time.

### **4.) Items having small communality values:**

Q8\_14R: Trust that printed information is true.

Q8\_15R: Use websites ending in .com.

Q8\_16R: Verify the information against things I've heard from my friends or family.

**5.) Items that did not have substantial loadings on any factor after EFA performed:**

Q9\_7: I feel like I spend an appropriate amount of time looking for health information online.

Q9\_10: I can use online search strategies such as quotes and dashes to narrow my searches for health information.

Q11\_10: I feel comfortable making educated guesses about my own health.

**Appendix F: Variance Accounted For Across Factors Before and After  
Extraction and Rotation**

Factor	Initial Eigenvalues			Extraction Sums of Squares Loadings			Rotated Sums of Squares Loadings
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	
	1	20.31	39.83	39.83	19.87	38.97	
2	4.18	8.20	48.02	3.77	7.40	46.36	15.344
3	2.49	4.87	52.90	1.84	3.60	49.96	8.674
4	2.17	4.26	57.15	2.04	4.00	53.96	10.206
5	1.92	3.77	60.92	1.33	2.60	56.56	5.609
6	1.39	2.72	63.64	1.01	1.99	58.55	12.494
7	1.28	2.50	66.14	1.22	2.40	60.94	11.143
8	1.09	2.13	68.27	0.72	1.40	<b>62.35</b>	6.563

## Appendix G: Factor Loadings for Remaining Phase Two Survey Items

This table reflects the factor loadings included in the rotated pattern matrix that resulted from the exploratory factor analysis.

Item	Factor							
	1	2	3	4	5	6	7	8
Q4_2	<b>1.035</b>	0.024	0.019	0.069	0.011	-0.169	-0.072	-0.126
Q4_16	<b>0.981</b>	-0.056	0.021	0.077	0.011	-0.115	-0.021	-0.074
Q4_6	<b>0.761</b>	-0.019	0.051	0.008	-0.009	0.055	-0.018	0.097
Q4_1	<b>0.712</b>	0.065	-0.042	0.041	-0.061	0.020	-0.152	0.105
Q4_19	<b>0.704</b>	-0.027	0.136	0.053	0.040	-0.020	0.180	-0.169
Q4_18	<b>0.683</b>	-0.026	0.066	0.041	0.080	-0.211	0.209	0.150
Q4_15	<b>0.616</b>	-0.033	-0.121	-0.026	0.064	0.211	-0.052	0.199
Q1_1	<b>0.581</b>	0.071	-0.138	-0.122	-0.092	0.198	0.021	0.153
Q4_8	<b>0.579</b>	0.021	0.009	-0.091	-0.006	0.026	-0.239	<b>0.566</b>
Q4_5	<b>0.567</b>	0.021	-0.022	0.023	0.118	0.192	-0.014	-0.043
Q4_10	<b>0.563</b>	0.002	0.069	0.067	0.012	-0.065	-0.028	<b>0.415</b>
Q1_5	<b>0.545</b>	0.042	-0.099	-0.197	-0.017	0.345	0.154	-0.081
Q1_2	<b>0.539</b>	0.098	0.002	0.012	-0.058	-0.067	0.410	-0.082
Q4_3	<b>0.495</b>	0.078	0.043	-0.079	-0.014	0.469	-0.147	0.002
Q115_3	0.095	<b>0.963</b>	-0.012	-0.009	-0.028	-0.140	-0.080	0.002
Q115_5	0.067	<b>0.928</b>	0.027	-0.070	-0.056	-0.119	0.015	-0.027
Q115_6	0.020	<b>0.897</b>	-0.082	-0.011	-0.084	0.000	-0.027	0.042
Q115_10	-0.040	<b>0.859</b>	-0.027	-0.040	0.059	0.011	0.078	-0.087
Q115_7	-0.013	<b>0.801</b>	-0.084	-0.094	0.050	-0.027	-0.007	0.162
Q115_1	0.128	<b>0.798</b>	0.017	-0.010	0.008	-0.207	0.018	0.023
Q115_11	-0.112	<b>0.767</b>	-0.046	-0.037	0.043	0.133	-0.010	0.049
Q115_8	-0.025	<b>0.672</b>	0.024	0.019	0.022	0.203	0.000	-0.046
Q115_12	0.032	<b>0.657</b>	0.072	-0.060	-0.028	0.130	0.107	-0.116
Q8_10	0.003	-0.121	<b>0.904</b>	-0.159	-0.007	-0.122	-0.030	0.091
Q8_2	0.017	-0.019	<b>0.877</b>	-0.274	0.012	-0.083	0.031	0.038
Q8_3	-0.035	-0.051	<b>0.828</b>	-0.078	-0.032	0.057	-0.008	0.092
Q8_7	-0.074	0.105	<b>0.699</b>	-0.013	-0.049	0.049	0.030	-0.070
Q8_11	-0.045	0.039	<b>0.630</b>	0.020	-0.022	0.067	0.029	-0.154
Q9_7	0.038	0.135	0.270	0.130	-0.042	0.022	0.003	0.133
Q9_10	0.006	0.121	0.192	0.075	0.072	-0.007	0.081	0.158
Q9_11R	0.019	-0.102	-0.220	<b>0.901</b>	-0.078	-0.130	0.064	-0.024
Q9_22R	-0.030	-0.105	-0.200	<b>0.874</b>	-0.081	-0.081	0.003	-0.082
Q9_1	0.020	0.068	0.050	<b>0.606</b>	0.027	-0.026	0.019	0.155
Q9_8	-0.007	0.268	0.002	<b>0.553</b>	-0.016	-0.092	0.068	0.135
Q11_5	-0.015	0.176	0.125	<b>0.515</b>	0.067	0.208	-0.113	-0.079
Q11_3	-0.004	0.114	0.123	<b>0.479</b>	0.035	0.293	-0.078	-0.125
Q11_1	0.038	0.031	0.293	<b>0.410</b>	-0.021	0.166	-0.006	-0.038

Q10_4	-0.045	0.031	-0.084	-0.105	<b>0.975</b>	-0.111	0.033	-0.012
Q10_1	-0.022	-0.012	0.002	-0.008	<b>0.804</b>	0.010	0.034	-0.048
Q10_9	0.113	-0.029	0.006	-0.081	<b>0.660</b>	-0.029	-0.065	-0.019
Q1_3	0.218	-0.041	-0.032	-0.110	-0.105	<b>0.819</b>	0.040	0.037
Q1_13	0.297	-0.038	0.006	0.012	0.017	<b>0.493</b>	0.103	0.072
Q4_13	0.277	0.046	0.026	0.138	0.077	<b>0.441</b>	-0.069	0.075
Q1_15	<b>0.387</b>	-0.037	-0.141	-0.135	-0.018	<b>0.422</b>	0.193	0.187
Q11_10	-0.052	0.080	0.088	0.143	0.126	0.285	-0.018	0.066
Q1_18	0.139	0.020	0.044	0.087	0.025	-0.076	<b>0.718</b>	0.152
Q1_19	0.239	0.064	0.017	-0.086	-0.015	0.119	<b>0.648</b>	-0.057
Q1_16	<b>0.421</b>	-0.028	-0.093	0.096	0.013	0.063	<b>0.527</b>	-0.024
Q1_6	0.287	0.050	0.065	0.013	-0.031	0.192	<b>0.391</b>	0.064
Q1_8	0.226	0.017	0.017	-0.098	-0.068	0.132	0.118	<b>0.621</b>
Q1_10	0.150	0.036	0.048	0.110	0.033	-0.015	0.325	<b>0.456</b>



## Appendix H: Correlations Between Factors

Factor	1	2	3	4	5	6	7	8
1	1.00							
2	0.58	1.00						
3	0.33	0.53	1.00					
4	0.42	0.64	0.52	1.00				
5	0.36	0.40	0.32	0.37	1.00			
6	0.52	<b>0.67</b>	0.52	0.57	0.28	1.00		
7	0.58	0.57	0.37	0.40	0.23	0.59	1.00	
8	0.44	0.35	0.23	<b>0.21</b>	0.24	0.41	0.32	1.00

**Appendix I: Factor Reliability Values**

<b>Factor</b>	<b>Cronbach's Alpha</b>
1	0.942
2	0.941
3	0.845
4	0.851
5	0.807
6	0.878
7	0.910
8	0.883

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