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by

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## Abstract

Cancer patients have significant healthcare needs and are likely to encounter complex health information along the course of their treatment, making it important for that information to be accessible and understandable. Online health resources strive to improve existing gaps in access to health services and information. Nevertheless, basic digital and health literacy skills are necessary for using and understanding these services and information. eHealth literacy, defined as the “ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem,” is crucial for the successful uptake of online-based health tools. Research shows that individuals with high eHealth literacy display greater health information-seeking practices and better quality of life. Low adoption and use of online health interventions, however, has resulted in efforts to develop a more comprehensive assessment of eHealth literacy. The eHealth Literacy Questionnaire (eHLQ) is a measure of eHealth literacy not yet tested in US cancer patients, who have complex, time-sensitive healthcare needs. Furthermore, no studies have yet examined the relationships between eHealth literacy, cancer literacy, information processing styles, and its impact on mental health outcomes, such as patient anxiety. Using these factors, the current study surveyed a sample of cancer patients (n= 153) actively receiving treatment or follow-up in the oncology department at Temple University Hospital in Philadelphia, PA. The survey was used to assess patient characteristics, eHealth literacy (eHLQ), cancer health literacy (CHLT-6), information processing style (MBSS-Monitoring) and patient anxiety (HADS-A). This data was then used to examine the fitness of a unidimensional latent factor model for the eHLQ. Results were also used to assess

correlations between eHealth literacy, cancer literacy, information processing, and patient anxiety. Finally, moderation tests were performed to determine the effects of eHealth and/or cancer health literacy on the relationship between information processing style and anxiety level. The results indicate the eHLQ adequately fits a one-factor model, which incorporates its seven underlying domains under one construct. Also, engagement with digital services and cancer health literacy appears to be significantly associated with information processing. Through these findings, our study provides initial steps towards the application of a comprehensive eHealth literacy measure in the web 2.0 world, and how this variable correlates to cognitive-behavioral processes and affective outcomes in an underserved group of US cancer patients.

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## **Chapter 1: Introduction and Background Information**

### **Problem Statement and Background**

The widespread reach and accessibility to content on the Internet has reshaped how individuals' interface with the healthcare system and manage their specific health needs. Internet use has dramatically changed over the past twenty years; in 2000, nearly half of the American population did not access the Internet – by 2019, this number plummeted to approximately 10% (Perrin, 2020). The role the Internet plays in health information-seeking practices has also evolved. A trend analysis of the Health Information National Trends Survey (HINTS) reported that the US population is increasingly adopting the Internet as their primary health information resource, from 61% in 2008 to 74% in 2017 (Finney Rutten, 2019). Such ubiquitous use of the Internet and electronic health (eHealth) technology sources as hubs of health information underscores the significance of having both adequate health literacy but also eHealth literacy as a tool for patients to access, understand and incorporate valuable information in their health decisions.

Norman and Skinner's seminal work on eHealth literacy, called the Lily Model, operationalized this concept as the "...ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem." (Norman p.2, 2006). This model depicts eHealth literacy at the center of six overlapping types of literacy: science, health, computer, information, media, and traditional literacy/numeracy. Implicitly, this definition requires its differentiation from the concept of health literacy, one of several competencies that must be attained towards achieving adequate eHealth literacy. Parker and Ratzan's original

definition of health literacy continues to be widely utilized and describes it as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Parker, 2010). While validated health literacy measures have been widely available for decades, the literature, theoretical models, assessments and interventions on eHealth literacy have largely developed over the past 15 years. eHealth literacy has been addressed within the context of intentions to use health technology, usability testing studies, and intervention studies towards preventative care and health management (Apter, 2019; Nahm, 2019; Stein, 2018). Nevertheless, eHealth literacy testing, through inclusion of validated measures such as the 8-item eHealth Literacy Scale (eHEALS), is seldom included along with other patient-reported assessments in research studies, particularly those examining its association to health outcomes (Norman, 2006).

Low eHealth literacy can be hard to identify; data samples with individuals of higher educational attainment and greater access to informational resources are unlikely to detect those with eHealth literacy deficits (Taha, 2014; Park, 2014; Arcury 2020). While health information resources are adapted using guidelines of basic literacy and educational cutoffs, eHealth literacy scoring has a more recent history (Norman, 2006). The eHEALS, the most commonly utilized scale to assess eHealth literacy, has a scoring range from 8 to 40, where a score under 26 reflects “low literacy” and from 26-40 translates to “high literacy” (Richtering, 2017). While the eHEALS has been validated using diverse samples and different languages, an eHealth literacy measure that provides a more comprehensive examination of skills and processes necessary for adequate eHealth literacy that has been tested in diverse groups in the US is not yet widely

available. Furthermore, little is known about the association between eHealth literacy and other behavioral theoretical constructs that impact patient beliefs and behaviors.

### **Definitions of Health Literacy and eHealth Literacy and Relationship to Information-Seeking Behaviors**

Personal health literacy, as defined in Healthy People 2030, describes “...the degree to which individuals have the ability to understand, and use information and services to inform health-related decisions and actions for themselves and others” (Healthy People, 2030.) While this new concept underscores the relevance of health literacy for individuals in a healthcare setting, current data on the state of health literacy in the US population are largely unavailable. The 2003 National Assessment of Adult Literacy, conducted by the National Center for Education Statistics is the first, and only large-scale assessment of health literacy in a representative sample of the adult population in the United States (Kutner, 2006; Cutilli, 2009). Results from the 2003 NAAL showed only 12% of adults to have adequate health literacy proficiency (Lopez, 2022). Sociodemographic disparities in health literacy were also observed: adults 65 and older had the greatest proportion of below basic proficiency, Hispanics presented the lowest rate of health literacy compared to other racial/ethnic groups, and income and educational level were positively associated with health literacy (Lopez, 2022). Additionally, English-only speaking adults and those who obtained health information from their health provider were more likely to have greater literacy than Spanish-only speakers, and individuals who use radio and/or television as health information resources (Lopez, 2022).

While these findings are useful in establishing how health literacy might increase disparities, the absence of recent data that captures the growing influence of Internet-driven resources for health information and management lends credence to the need of ongoing assessment of health and eHealth literacy, and appropriate measures that describe differences in literacy in our current population. No population-based survey similar to the NAAL has been done to capture eHealth literacy to date; evidence instead comes from a small number of studies with varied populations and sample sizes. However, there is some evidence on how eHealth literacy affects different populations. For example, a 2016 systematic review of eHealth among underserved populations found that seeking health information, access to Internet and computers, higher education and greater overall health literacy and numeracy were associated with higher eHealth literacy in low-income, primarily urban populations. Nevertheless, this review also reveals that research into this topic is still scarce, and a predominant use of one- or two-item screening questions limits our understanding on the underlying factors that lead to poor eHealth literacy (Chesser, 2016). Analysis of eHEALS data from the 2020 CALSPEAKS survey with adults 65 and older in California reports some consistent findings with the Chesser review. Respondents of this survey who reported lower education and less frequent use and breadth of Internet-related activities had lower item scores and overall scores on the eHEALS (Berkowsky, 2021).

Norman's operationalization of eHealth literacy stresses its value as a problem-solving measure through the purposeful gathering and application of health knowledge to optimize experiences with care. Results from two cross sectional studies assessing adults' eHealth literacy determined higher literacy was associated with recurrent practices of

online information-seeking behavior, and an increased ability to discriminate between high- and low-quality health information sources (Li, 2014; Neter, 2012). As a prerequisite towards obtaining quality health information online, eHealth literacy is likely to enhance personal motivations to use online health resources, through consistent exposure to information that might enhance previous limitations with literacy in the healthcare setting. Indeed, findings from a 2017 survey on Internet usage for health services concluded that the frequency of use was associated with greater confidence in medical decision-making (Halwas, 2017).

The impact of eHealth literacy in information-seeking outcomes has been observed across different patient populations. In parents of children with severe illness, eHealth literacy was directly associated with information-seeking frequency (Knapp, 2011). COPD patients with higher eHealth literacy were found to possess more specialized health knowledge and more positive perceptions of their personal abilities to correctly comprehend health information resources online, compared to those with lower eHealth literacy (Stellefson, 2018; Stellefson, 2019). In seeking cancer-related support and information, a study determined individuals of lower eHealth literacy were less confident about finding cancer-related information and required more education about seeking information (Park, 2014). Additionally, an intervention on breast cancer survivors determined women with lower digital literacy were more likely to report difficulties using online support groups and exhibited greater computer-related anxiety pre-intervention; they also had higher distress before and after using online support information resources (Lepore, 2019). Importantly, this was one of the few studies that

attempted to connect levels of eHealth literacy to other theoretical constructs that might be related to health behavior outcomes.

### **Determinants of eHealth Literacy – the Role of Access**

eHealth interventions have been championed as tools to assist patients with health management tasks, for the purpose of bettering health outcomes and towards ameliorating the increasing demand in healthcare (Graffigna, 2013). Yet, in order to address eHealth literacy gaps, it is essential to identify some of the characteristics that increase the likelihood of lower literacy for technology-based resources, such as poor access to the Internet. A 2014 study on Latino patients determined that participants reported Internet access as a combination of at-home and alternative resources, such as Internet use at a public library (Victorson, 2014; Perrin, 2020). Older adults, who are increasingly likely to experience chronic illness and/or disability, tend to display lower eHealth literacy and computer experience (Choi, 2013; Lee, 2016; Levy, 2015). Furthermore, eHealth literacy has been shown to have some indirect effects in the association between mental health status and health information-seeking online (Chen, 2014).

An important consideration in understanding disparities in eHealth literacy is to acknowledge that such tools might not reach those without access to basic technology, technical expertise, and basic education (Office of the National Coordinator for Health Information Technology, 2010). To better characterize the impact of eHealth literacy in underserved communities, a few studies have assessed the impact of this skill on racial minorities, Non-English speakers, low income, and Medicare/Medicaid recipients. Assessment of low-income adults in medically underserved communities using the eHEALS revealed an interplay of multiple factors affecting eHealth literacy. These

include non-English as a primary language, older age, and low educational attainment (Knapp, 2011). Two studies looking at largely Hispanic and African American populations determined that more positive attitudes towards telehealth, mobile health (mHealth) resources (i.e. health apps) and use of the Internet to find health information were associated with higher eHEALS scores (Ghaddar, 2020; James, 2016). While future studies should continue to expand our understanding of eHealth literacy in underserved and hard-to-reach communities, healthcare systems must concurrently address the prevailing issue of unavailable technological infrastructure, health, and digital education, and consider future approaches to manage additional training due to advancements in technology (Kaper, 2019; Bevilacqua, 2021).

The fast-paced transformation of information communication technologies in health exhorts the need for continuous eHealth literacy education, particularly as technology becomes more sophisticated. A number of studies on predictors of eHealth literacy have established a positive association between higher education attainment and greater eHealth literacy (Tennant, 2015; Werner, 2011; Xie, 2011). Low eHealth literacy can also impact care providers; a study on caregivers of older adults with cognitive impairments showed that in caregivers with less than a high school-level education, eHealth literacy was associated with caregiver burden (Wang, 2020). In a sample of ethnically diverse sample of people with diabetes, low patient portal use and interaction with the features was associated with lower education (Sarkar, 2011). As a critical factor of socioeconomic status and traditional literacy, individuals with low educational attainment experience critical challenges to develop greater health and digital literacy.

In the United States, an aging Baby Boomer population will have a dramatic impact on the demands of care, an area where health technology could provide assistance (Bluethmann, 2016). Yet, eHealth literacy and technology-based interventions can be challenging for older adults, both because of age-related impairments, and keeping up with the skills necessary to use them. Such age barriers have been observed in various studies of older adults, who show a lower likelihood to be interested in and/or use health technology and even find some of the educational resources too challenging to use (Gordon, 2018; Graetz, 2016; Choi, 2013).

Despite the challenges for many to use these technologies, healthcare organizations and its providers have, for the most part, embraced the adoption of Internet-driven health tools. This has been largely prompted by governmental financial incentives, predicting that their implementation will optimize workflow and have positive effects on patient outcomes (Buntin, 2011). Nevertheless, studies have shown that diversity across healthcare organizations, perceived value of in-person communication by patients, and the degree of comfort with evolving technology are crucial factors that influence adoption and application of eHealth technology by healthcare professionals, who are often the link between the technology and patients (LeBlanc, 2020; Townsend, 2015; Granja, 2018).

### **Outcomes Associated with eHealth Literacy**

A 2014 systematic review on eHealth literacy interventions in older adults found that none of the studies evaluated used a single health determinant as an outcome measure (Watkins, 2014). While this is an inherent limitation towards understanding the overall impact of eHealth literacy, some evidence is emerging on the relationship between eHealth literacy and health protective behaviors, which themselves can impact

health outcomes. An assessment on the influence of finding assistance to navigate online health sources found that securing online technical support increased eHealth literacy and improved perceived health outcomes (Hayat, 2017). Two cross-sectional studies also determined greater critical eHealth literacy to be a mediating factor for positive health behaviors, including adequate sleep time, healthy diet, and physical exercise (Hsu, 2014; Mitsutake, 2016). A study using the Japanese version of eHEALS found a significant positive association between eHealth literacy score and colorectal cancer knowledge (Mitsutake, 2012). Further, an analysis of eHealth literacy, information-seeking and patient-provider consultations found higher eHealth literacy was indirectly associated with more frequent visits to providers through greater search for health information (Schulz, 2017). In diabetes management, patient portal use has been associated with improved health outcomes, such as lower A1C levels at follow-up appointments, as well as lower medication non-adherence, compared to non-users (Lau, 2014; Sarkar, 2014). Parental management of pediatric asthma using a disease-specific portal also found users to report improved communications with providers, more awareness of their child's treatment and reduction in the number of asthma attacks compared to controls (Fiks, 2015). Despite this, only a handful of studies have attempted to connect eHealth literacy levels with health outcomes, making this an important area of further research.

### **eHealth Literacy and Cancer**

Individuals diagnosed with cancer are an important target for health communication and information technologies, due to their time-sensitive need for access to healthcare providers and services, and exposure to highly complex medical information. eHealth interventions have been tailored to address various cancer-

associated conditions, including management of cancer-related fatigue, telerehabilitation for patients with head and neck cancers, and remote physical activity education for cancer survivors (Seiler, 2017; Cartmill, 2016; Rossen, 2019). Moreover, cancer patients have widely adopted the Internet as a source of health information; results from a 2019 study reported more than 90% of cancer patients used the Internet as a source of health information (Braun, 2019). Nevertheless, older adults, who are most likely to be diagnosed with cancer, have been found to have decreased confidence navigating online resources and retrieving needed health information (Arora, 2008, Kinnane, 2010; Eng, 2020).

A cross-sectional survey of US cancer patients and their caregivers report widespread availability of Internet access and smartphone ownership, even among urban populations with lower education (Leader, 2021). While increased access to these tools can enable access to information on a larger scale, cancer patients continue to show low adoption to online health resources, such as patient portals. A US survey of cancer patients found that of over 25,000 respondents, only 18% had accessed health technology tools provided through their healthcare system. Significantly, older age, low educational attainment and being African American were significantly associated with lack of adoption of such resources (Abdel-Rahman, 2021). Results from a focus group study of stakeholders geared towards identifying issues in digital health technology implementation in cancer found consumers felt the continuing evolution of health technology, combined with disease-related effects and their personal circumstances make digital health technology particularly challenging (Kemp, 2021). Similar findings have been measured in performance analyses; a study evaluating the ability of cancer patients

to perform cancer-related online search tasks found most participants had trouble completing tasks, and most used non-specific terminology and/or did not verify the source of the information (Lange-Drenth, 2021).

It should be noted the role of geography. A 2021 scoping review (Verma, 2021) on the eHealth literacy of cancer patients and caregivers found that of eleven identified studies, only two occurred in the United States. One focused on cancer caregivers (Song, 2017) and another on older adults with cancer (Hoogland, 2020). A 2017 study by Song and colleagues assessing the eHealth literacy of partners of newly diagnosed prostate cancer patients found increasing eHealth literacy to be associated with a greater knowledge of treatment options and higher likelihood of obtaining a second medical opinion (Song, 2017). Hoogland's 2020 cross-sectional survey of 198 cancer patients found patients 65 and older to be more likely to have lower eHealth literacy and feel less able to seek relevant health information online, or answer health questions (Hoogland, 2020). While these findings endorse the value of eHealth literacy testing towards understanding patient engagement with health technology and online information, they also reflect an urgent need for more comprehensive assessment of eHealth literacy in conjunction with other information-seeking constructs in US cancer patients.

### **State of Research in eHealth Literacy Interventions**

While findings of these interventions on chronic disease management are promising, assessments for eHealth literacy in eHealth interventions are rare. While the previously listed findings are meaningful, a dearth of research exists on the correlation between eHealth literacy and disease incidence, morbidity, or mortality, as well as a cohesive description of what eHealth literacy is and how to best measure it or its

relationship to health behavior theory constructs. Such a gap in knowledge poses a significant challenge towards understanding the range of eHealth literacy in the population and developing educational interventions that might address existing disparities. These factors warrant continued research and refinement of the concept and measurement of eHealth literacy (Neter, 2019), a driving force for this study.

### **Theoretical Frameworks & Measurements**

This research is driven by four theoretical frameworks: the eHealth Literacy Framework the Cognitive-Social Health Information-Processing (C-SHIP) Model, the Health Literate Care Model, and Cancer Anxiety.

#### **The eHealth Literacy Framework (eHLF) and eHealth Literacy Questionnaire (eHLQ)**

In 2015, Kayser and colleagues published an alternate framework to Norman and Skinner's Lily Model of eHealth literacy, which included user-specific abilities, knowledge, and perceptions, to also include necessary health and technological skills, all framed within the specific resources and systems of the healthcare environment ("health care context dimension") (Kushniruk, 2012). The novel framework was purposefully designed to account for the changing nature of technology, and thus the need of an individual to continuously learn and adapt in order to maintain adequate eHealth literacy. Through adaptation of a user-task-context matrix design, investigators developed a 7-domain design (Kushniruk, 2012). Domains 1, 2 and 3 correspond to the user, and their knowledge regarding their health, how they interact with information, and skills working with technology. Domains 4 and 5 correspond to the task dimension, which refers to access to the right technology for the task, and for the needs of the patient. Overlapping

of the user- and task dimension- results in the emergence of domains 6 and 7; both domains focus on the patient-user's self-reported reactions to the value of eHealth and their sense of control and confidence using technology within the healthcare context (Kayser, 2015).

Norman and Skinner's Lily Model describes the relationship between six individual skills, three analytical skills (traditional literacy and numeracy, information literacy media literacy) and three context-specific skills (health literacy, computer literacy, science literacy) and how these contribute to eHealth literacy. Each of the distinct six literacies, as the petals of a lily, "...feed the pistil (eHealth literacy), and yet the pistil overlaps the petals, tying them together." (Norman, 2006). Like in the Lily Model, the eHLF states that continued access to working technology and the Internet is an imperative towards achieving adequate eHealth literacy. Additionally, the user dimension domains on this framework closely resemble the context-specific skills (health, computer, and science literacy) of the Lily Model, recognizing that this particular set of competencies remain relevant in modern health technology. However, unlike Norman and Skinner's model, Kayser and colleagues' user-task-context matrix focuses on the user's needs and interactions, providing a more individualistic perspective. Within this structure, domains 6 ("feel that using technologies is beneficial") and 7 ("feel in control and secure when using technologies") align with well-established behavioral theory and constructs (Kayser, 2018). For instance, using the Theory of Planned Behavior as an example, the patient-user attitudes towards using the technology, and perceived self-efficacy using these tools, within the normative of the healthcare context might impact intentions and/or use of the technology (Bensley, 2004). Through its

interdisciplinary development and message, the eHealth Literacy Framework also contains a process model for the requirements of information technology; this model calls for the participation of both IT designers and users to contribute to new technology using a user-task-context matrix (Norgaard, 2015). Through this framework, technology's aim is to benefit its consumer, by adapting to their limitations, and reducing barriers that might discourage the use of health technology, such as distrust and fear of privacy breaching.

In 2018, Kayser and colleagues published the initial validation of the 35-item eHealth Literacy Questionnaire (eHLQ), based on the 7-domains of the eHealth Literacy Framework (Table 1) (Kayser, 2018). Like its framework, this instrument reflects the problem of a growing complexity towards capturing the set of skills, personal factors and environmental context that can accurately capture eHealth literacy. Recently, a measurement invariance study looking at group differences using the eHLQ showed lower scores were associated with older age (total effects between -0.37 and -0.21) and higher scores were associated with higher education (total effects between 0.21-0.25). The use of information communication technology showed some mediating effects for both of these interactions (Cheng, 2021). Importantly, however, this measure has only been used in fairly homogenous populations in Europe and has not been validated in the US or with a cancer population who may be more motivated to use technology for information seeking.

On the other hand, since its original publication, the eHEALS has become one of the most widely used instruments to assess eHealth literacy. While the low burden of this measure makes it desirable, issues of validity and questions about the theory behind the

eHEALS have been raised. A 2021 systematic review of eHealth measures suggests variability between studies on the structural validity, reliability, and measurement invariance of the eHEALS. Furthermore, the authors contend that the advancement of Internet technology and its use make the Lily Model an inadequate framework for the development of a tool that appropriately captures eHealth literacy differences in the present day (Lee, 2021). Thus, there is currently not a good standard measure of eHealth literacy, making research on a more comprehensive measure such as the eHLQ important in a more diverse, U.S. population.

<b>Domain</b>	<b>Definition</b>
1. Ability to process information	Able to read, write and remember, apply basic numerical concepts, and understand context-specific language (e.g., health, IT or English) as well as critically appraise information. Know when, how and what information to use.
2. Engagement in own health	Know about basic physiological functions and own current health status. Aware of risk factors and how to avoid them or reduce their influence on own health as well as navigating the health care system.
3. Ability to actively engage with digital services	Being comfortable using digital services for handling information.
4. Feel safe and in control	Feel that you have the ownership of personal data stored in the systems and that the data are safe and can be accessed only by people to whom they are relevant (own doctor, own nurse, etc.).
5. Motivated to engage with digital services	Feel that engaging in the use of digital services will be useful for them in managing their health.
6. Access to digital services that work	Have access to digital services that the users trust to be working when they need it and as they expect it to work.
7. Digital services that suit individual needs	Have access to digital services that suit the specific needs and preferences of the users. This includes responsive features of both IT and the health care system (including careers) as well as adaptation of devices and interfaces to be used by people with physical and mental disabilities.

Table 1. The 7 constructs of the eHealth Literacy Questionnaire (from Kaiser, 2018, Multimedia Appendix 2)

## **The Cognitive-Social Health Information-Processing (C-SHIP) Model**

The Internet has made health information resources readily available to the general population. Nevertheless, different individuals can show differences in behavioral responses to health threats, as described in Miller's work towards identifying monitoring processing styles (Miller, 1987). Her research proposes cognitive-affective profiles exist in the ways individuals process information regarding their health, and how this information is then reflected in positive or negative health behaviors (Miller, 2015). This framework, called the Cognitive-Social Health Information-Processing Model, or *C-SHIP*, describes how five specific mediating factors involved in the processing of cancer health information led patients to perform (or avoid) health protective behaviors (Krantz, 1998; Roussi, 2014). The five cognitive and affective factors involved relate to how individuals react to adverse health events. They are defined below.

1. *Health-relevant knowledge and perceptions*, which become part of the patient's knowledge system, and becomes encoded as either schematic or conceptual memories. Schematic memories are associated with prompting affective responses based on memories of personal health-related episodes. In contrast, conceptual memories are associated with strategies related to coping with a health scenario, including evaluation and decision-making (Leventhal, 1979; Miller 1987).

Research by Miller on the assessment and classification of information processing styles identified two primary categories. High monitoring, also referred to as 'monitors,' are those who are more likely to seek and appraise health information, and appear to amplify health threats, which result in greater distress and fear from outcomes, from testing to treatments (Miller, 1995; Sherman, 2015). In contrast, low

monitoring individuals, also called ‘blunters,’ are less likely to engage in information-seeking behavior and exhibit lower levels of stress related to their health condition.

Nevertheless, blunters are also less likely to adhere to recommendations for screening and treatment.

2. *Health-relevant beliefs and expectancies* are the ways a patient perceives a threat to their health. This component includes the individual’s perception of their health outcomes, their expectations regarding treatment, and self-efficacy related to their ability to adhere to a recommendation or treatment.
3. *Health-relevant values and goals* relates to a patient’s perception of the pros and cons of following a particular health recommendation. This perception depends on various considerations, such as the degree of difficulty of adhering to the behavior, the patient’s outcome expectations and their beliefs, such as if their behavior has meaningful health benefits.
4. *Health-relevant affects and emotion* describes the elicitation of positive and negative affects based on health experiences, and how such affects might impact the decision to engage with health protective behaviors.
5. *Health-relevant self-regulatory competencies* consist in necessary mental operations, including self-cuing, self-monitoring, and self-instructions, which are necessary for patients to adhere to long-term health regimens, particularly for individuals who are managing chronic health conditions (Krantz, 1998; Miller, 2015).

The *C-SHIP* model has been previously used as the theoretical foundation in the association between cognitive and affective factors and seeking cancer information

online. A study on rural breast cancer patients assessing the different variables in *C-SHIP* determined each of the 5 factors was associated with online cancer information-seeking behavior, particularly for information on cancer experiences. Furthermore, the study found that patients with more negative appraisal of their health were more likely to seek out cancer information online (Shaw, 2008). This finding aligns with Miller's description of information processing styles among monitors. A 1999 literature review on factors influencing preventative oophorectomy in women with family history of ovarian cancer determined monitors reported greater distress based on their cancer risk, and were more likely to consider prophylactic surgery, compared to blunters (Miller, 1999). But notably, this model has not been used in association with eHealth Literacy and no studies have tested whether the model is associated with skills as measured by the eHLQ.

### **Health Literate Care Model and its Relationship to Disease Specific Literacy**

The value of patient engagement with health decision-making and high-quality healthcare experiences are important components of quality healthcare delivery and improving patient outcomes. The Care Model, also known as The Chronic Care Model, was developed to guide healthcare organizations to maximize the benefits of their services to patients (Coleman, 2009). This model is comprised of 6 care elements at different levels within a healthcare organization. Each of the elements describes ways to leverage the patient-provider experience to ensure patients are educated, empowered, and motivated to support their own care, with the guidance and support of the healthcare organization (Koh, 2013.) An enhanced version of the Care Model, which foments "the delivery of safe, effective and collaborative care to patients," called the Health Literate Care Model, underlines the significance of adequate health literacy towards more

proactive care management and informed shared decision-making by patients, particularly those who experience chronic illnesses (Wagner, 1996; Koh, 2013.)

The Health Literate Care Model results from the incorporation of health literacy-specific interventions from the Agency for Healthcare Research and Quality (AHRQ) Health Literacy Universal Precautions Toolkit into the six traditional elements of the Care Model: 1. Health care organization; 2. Self-management support; 3. Delivery system design; 4. Decision Support; 5. Clinical information systems; and 6. Community partners) (Koh, 2013; DeWalt, 2010.) Under this new framework, health literacy becomes a central component to each element. Some examples of these include the emergence of health literacy teams within health organizations to spearhead interventions towards healthcare providers, creating educational roles and activities to assist patients to become more proficient in their care management, and developing community-based partnerships to extend available resources that can improve health literacy in patients. (Koh, 2013.)

A critical component of gauging the success of a framework like The Health Literate Care Model is the availability of patient assessments that measure literacy outcomes of such interventions. Health literacy assessments used to identify individuals with limited literacy are widely available. Some of the commonly utilized instruments include The Test of Functional Health Literacy (TOFHLA) and the Rapid Estimate of Adult Literacy in Medicine (REALM) (Parker, 1995; Davis, 1993). While these instruments are widely used in research settings, the broad scope of these assessments fail to address topics of specific relevance to patients with specific disease information needs, such as cancer, and do not accurately identify individuals with limited domain specific health literacy (Dumenci, 2014). In the case of conditions such as cancer, which require

the acquisition of specific, complex medical information, adequate general health literacy might not be representative of a patient's cancer-specific knowledge. This disparity was shown in a 2021 cross-sectional study, screening cancer patients using a general health literacy tool (Brief Health Literacy Screening Tool [BRIEF]) and a cancer-specific health literacy measure (Six-Item Cancer Health Literacy Test [CHLT-6]). Of particular significance, this study found 16.8% of participants displayed adequate health literacy on the BRIEF but showed inadequate cancer health literacy based on their CHLT-6 scores (Hyatt, 2021). These findings suggest that within a care model that reinforces health literacy in a disease-specific population, such as cancer, measures used to determine literacy level must contain questions that are reflective of the type of medical terminology the average patient is expected to understand to be engaged in their care. Importantly, there has also been no connection of these types of measures with overall eHealth literacy to assess whether context specific literacy is associated with or ameliorates potential negative health outcomes related to low eHealth literacy.

### **Cancer Anxiety**

Anxiety is a psychological condition that is commonly observed in cancer patients (Naser, 2021). The risk of the disease, impact of treatment, complex health information, medical costs, just to name a few factors, can impact the mental quality of life of the patient (Mitchell, 2013). Curran and colleagues reviewed the frameworks that have been developed to address anxiety cancer, mostly in reference to fear of reoccurrence (Curran, 2017). Observing the absence of a model focused on an active cancer experience, the Cancer Related Anxiety model was developed. This new model, which consists of the combination of factors of previous cancer-related models, emphasizes cognitive and

psychological processes related to the nature of cancer, and divides them into three sectors: self, other, and world. In a flow diagram, anxiety takes the central place, fed by a cancer diagnosis and following responses to the threat of illness and death, the anxiety response might branch out into different ways of coping. On one hand, helpful coping provides a mechanism for processing fear and recognizing controllable versus uncontrollable factors in order to assimilate the diagnosis and have better cognitive responses that might reduce anxiety. On the other hand, excessive control attempts, such as threat monitoring or avoidance, can result in lower engagement with the treatment process, reinforcing poor coping mechanisms and increasing anxiety. The middle (light blue level), which focuses on contextual factors, describes the role of cancer in their functioning (self), the impact of support from family, healthcare providers and other supporting entities (other), and additional stressors from daily living (world). Finally, the outer ring (dark blue) addresses pre-existing schemas and traits. For the “self,” this involves factors such as perceived self-worth, mental health history, threshold towards uncertainty and coping styles. The “other,” entails the sense of stability and security from those around the patient. “World” schemas and traits relate to personal values, beliefs, and worldview (Curran, 2017). This complex model provides a multi-level, multi-source factors that are in constant interaction, and has the potential to improve or worsen anxiety throughout the cancer care continuum.

## **Current study**

### ***Rationale***

To our knowledge, the research conducted in this study represents the first application of the eHealth Literacy Questionnaire in a US patient population, and the first

instance this concept is evaluated along with health information processing, cancer health literacy and anxiety. It will also identify whether the eHLQ could have a more parsimonious structure, making it easier to use and interpret in future intervention studies. The increasing development and implementation of patient health technology calls for basic understanding of how patients navigate, utilize, and interact with these tools, and how this interaction is associated with health behavior outcomes. Previous studies have provided information on patient outcomes and general characteristics of users and non-users of eHealth resources, such as patient portal adoption rates (Han, 2019; Sakaguchi-Tang, 2017; Fraccaro, 2017).

The decision to center this work on eHealth literacy was based on several factors. First, health technology tools are becoming widely available across healthcare organizations throughout the US. Second, such technology is geared towards assisting patients to manage their own health history, enhance patient-provider communications, and facilitate access to services. Individuals with chronic conditions like cancer that require frequent engagement with healthcare would be expected to benefit from these resources (Jha, 2010). Lastly, government incentives for providers and healthcare systems are available to encourage clinicians and medical staff to promote these features (National Learning Consortium, 2013). To our knowledge, this study provides a novel assessment of eHealth literacy and its relationship to specific and relevant outcomes in the cancer patient population, such as anxiety, as well as an opportunity to assess the validity and utility of the eHLQ in a more diverse, U.S.-based population. Figure 1 illustrates the conceptual model of how an assessment of eHealth Literacy could be associated with information processing style, use of the internet to seek health

information and cancer health literacy in a cancer patient population and the outcome of anxiety.

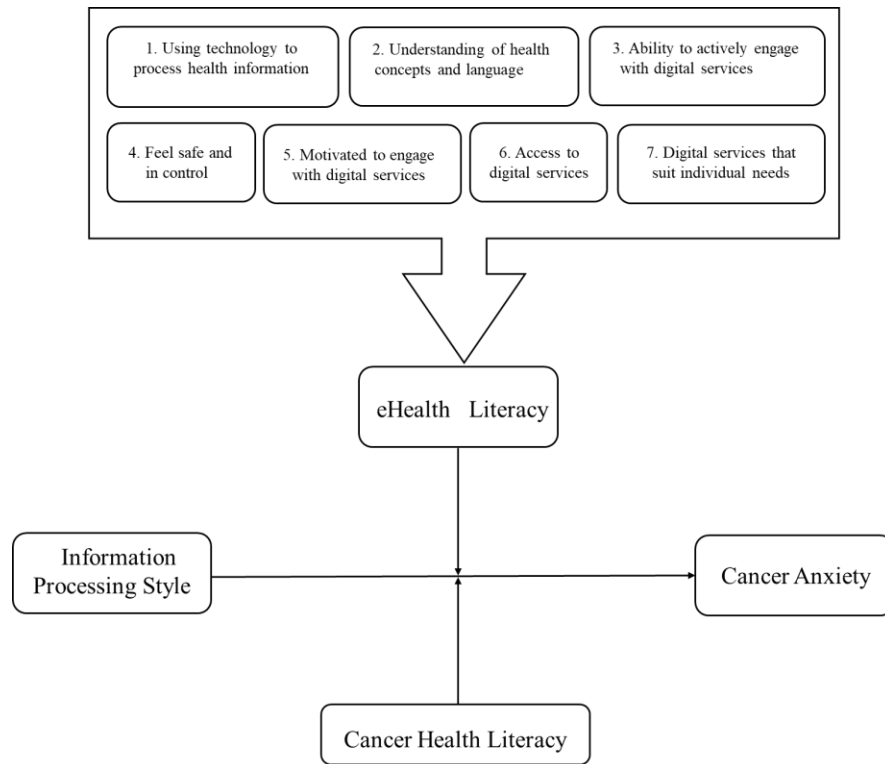


Figure 1. Conceptual Model on the impact of eHealth literacy, information processing style and cancer health literacy on patient anxiety

The primary objectives of this study are to: 1. Assess the state of the literature in using eHealth literacy in intervention studies and identify the gaps in research for future priorities; 2. Assess validity of the eHLQ in a US cancer patient population; and 3. Test if information processing and cancer health literacy moderate the relationship between eHealth literacy and cancer anxiety. Administration of the eHLQ in our patient population represents the first instance this instrument has been administered in a sample of primarily racial/ethnic minority respondents in the US. Analysis of the measure's factor structure allows its comparison to previous assessments in Australia and the

Netherlands, where researchers concluded a multi-domain structure is most fitting for score interpretation of the eHLQ (Kayser, 2018; Cheng, 2021).

### ***Research Objectives and Specific Aims***

This study has three specific aims, described below:

**Aim 1:** To assess if the 7 domains of the eHealth Literacy Questionnaire will fit a unidimensional latent structure.

**Research question 1:** Will eHLQ data from a US sample of urban, underserved cancer patients fit a one-factor model?

**Aim 2:** To examine the relationship between eHealth literacy and cancer health literacy to information processing and patient anxiety.

**Research question 1:** Will the seven domains of the eHLQ show an association with higher anxiety in cancer patients?

**Research question 2:** Will cancer health literacy show an association with higher anxiety in cancer patients?

**Research question 3:** Will the seven domains of the eHLQ show a relationship with higher information processing (monitoring) in cancer patients?

**Research question 4:** Will cancer health literacy show a relationship with higher information processing (monitoring) in cancer patients?

**Aim 3:** To assess the moderating effects of the seven domains of eHealth literacy and cancer health literacy between information processing and anxiety.

**Hypothesis 1 to support aim 3:** the seven domains of eHealth literacy will each show moderating effects between information processing and patient anxiety.

**Hypothesis 2 to support aim 3:** cancer health literacy will show moderating effects between information processing and patient anxiety.

### *Study Overview*

This cross-sectional study involved a one-time survey of patients at the Temple University Hospital oncology department in Philadelphia, PA. Temple University Hospital is located in the heart of North Philadelphia amidst a patchwork of diverse, disadvantaged, minority neighborhoods. The hospital's catchment area includes a population which is over 75% Black and Latino. The protocol for data collection, assessment and analysis was developed for implementation in summer and Fall 2022 (June to November). Research protocol was submitted and approved by the Temple University Institutional Review Board (protocol number: 29400). Prior to survey administration, survey administrators assessed participants' inclusion criteria. Those unable to read or understand English were excluded from the study. The initial sample size target was 300 participants; the final recruited sample consisted of 155 respondents.

The survey packet administered to patients was titled "eHealth Literacy, Coping Style and Cancer Literacy Outcomes Survey." This survey contained consent information for participants, along with three questions to determine eligibility for participation: Have you received a cancer diagnosis? Are you currently getting treatment or follow-up care for your cancer? Are you 18 years or older? Individuals who replied yes to the three questions, had the ability to complete the English survey independently or with the assistance of a student worker, and provided verbal consent were eligible to participate. Time of administration of the survey varied depending on the need of assistance from a survey administrator, however on average patients spent approximately 20 minutes

completing the survey. Upon completion of the survey, respondents were given a \$15 gift card to Walmart or Target to thank them for their participation.

### **Overview of the three manuscripts**

The current dissertation is formatted under the three-paper model. Under said model, dissertation research activities result in three manuscripts, which can then be submitted for peer review and publication in scientific journals. The three manuscripts below individually describe a portion of the development, application, and analysis of the dissertation study.

In manuscript one, we assess the eHLQ in a novel population: primarily Black/African American, active cancer patients in Philadelphia. The data collected was used to determine if the eHLQ factor structure supports previous analysis performed in Dutch and Australian participants (multidimensional structure) or if there is evidence that a more parsimonious factor model is fitting in this current sample.

The second manuscript explores how eHealth literacy, cancer literacy and information processing are associated with anxiety (psychosocial outcome). Such analysis generated odd ratios that elucidate the existence of possible correlations between two types of literacy and outcomes previously associated with the experience of undergoing cancer care and navigating complex health information. In the final manuscript, we will examine possible moderating effects of eHealth literacy and cancer health literacy between information processing and anxiety. Using interaction models, we gauged if literacy ameliorates anxiety for patients with different information processing styles. Such results might provide new insight on specific patient needs based on their information-seeking preferences and how this impacts their mental health.

**Description of Manuscript 1: Novel Factor Structure Assessment of the eHealth Literacy Questionnaire (eHLQ): eHealth Literacy among urban cancer patients in the United States**

**Aim 1:** To assess if the 7 domains of the eHealth Literacy Questionnaire will fit a unidimensional latent structure.

*Research Question 1: Will a unidimensional latent factor structure show a similar fit from the original validation study sample?*

***Study sample***

Aim 1 was addressed using cross-sectional survey data collected from oncology patients at Temple University Hospital between June and November 2022 who met the above outlined eligibility criteria.

***Survey measures***

eHealth literacy was assessed using the eHealth Literacy Questionnaire (eHLQ) (Stellefson, 2011.). The eHLQ is a 35-item measure that uses 4-point Likert response scales. As noted earlier, the eHLQ items addresses 7 overarching domains from the eHLF, containing between 4 to 6 items per scale: (1) ability to process information (5 items), (2) engagement in own health (5 items), (3) ability to engage with digital services (5 items), (4) feeling safe and in control (5 items), (5) motivation to engage with digital services (5 items), (6) access to digital services that work (6 items), and (7) digital services that suit individual needs (4 items). A Likert-type score of 1 to 4 is used for each item. According to published scoring protocols for the measure, items included in each domain are added to generate a mean domain score, ranging from 1 to 4. Thus, seven individual mean scores are calculated from the questionnaire, one for each of the domains

(Kayser, 2018). Higher scores indicate higher eHealth literacy and all items within each scale are weighted equally (Cheng, 2021).

Initial validation of the eHLQ factor structure was performed using a sample of 475 Danish respondents; the analytic approach was Bayesian confirmatory factor analysis. Results from Kayser et al. supported a 7-factor model with satisfactory item loadings. Composite scale reliability ranged between  $\alpha = 0.75$  (scale 3)-0.87 (scale 5). Item response theory analysis showed no disordered thresholds across scale items.

### *Statistical analysis*

The research question for aim 1 examined a unidimensional latent factor model for the items included in the eHLQ for goodness-of-fit. Previous assessment of the eHEALS, the most prevalent assessment of eHealth literacy in peer-reviewed research, has supported a unidimensional structure for this construct (Norman, 2006). The validation of the eHLQ suggested a seven-domain score system for the 35-item measure, with each domain scored using the items' mean (4, 5 or 6 items). While the eHLQ items delve into perceived technology-related skills, motivations to seek health information online, and access to resources, administration of the survey and interpretation of multiple scores can limit its practical use in research settings. A one-factor model of the eHLQ, and the potential calculation of a global score from the seven domains, would simplify how the scores are reported and interpreted, how respondents compare to each other, and how evidence-based interventions might impact eHealth literacy over time.

MPlus was used to estimate a unidimensional factor model. Model fit was assessed through chi-square test and three fit indices (Chi-square index of fitness, comparative fit index [CFI], the Lewis-Tucker index [TLI] and Root Mean Square Error

of Approximation [RMSEA]). Index cutoffs for fitness assessment of the latent model included a CFI score equal to or above 0.95, a TLI score equal to or above 0.95, and a RMSEA score equal to or below 0.07.

### ***Summary***

The eHLQ provides a comprehensive, multi-domain configuration to assess eHealth literacy. Nevertheless, its interpretation might pose challenges, particularly when administering in a clinical setting. A unidimensional factor for eHealth literacy, providing a global score for all items, would provide results that would be more easily interpretable by providers and patients, which might encourage a more widespread application of the questionnaire as a resource to identify and improve disparities in eHealth literacy.

### **Description of Manuscript 2: eHealth and Cancer Health Literacy in an Urban Cancer Patient Population: The Impact of Literacy on Information Processing Style and Patient-Reported Anxiety**

**Aim 2: To examine the relationship between eHealth literacy, cancer health literacy and information processing to patient anxiety.**

*Research Question 1: Will the seven domains of the eHLQ show an association with higher anxiety in cancer patients?*

*Research Question 2: Will cancer health literacy show an association with higher anxiety in cancer patients?*

*Research Question 3: Will the seven domains of the eHLQ show a relationship with higher information processing (monitoring) in cancer patients?*

*Research Question 4: Will cancer health literacy show a relationship with higher information processing (monitoring) in cancer patients?*

### *Study sample*

Aim 2 was addressed using the same cross-sectional survey data used on Aim 1, collected from oncology patients at Temple University Hospital between June and November 2022.

### *Survey measures*

1. eHealth literacy: eHealth literacy was assessed using the eHealth literacy questionnaire (eHLQ), as described above.

2. Information monitoring: The Miller Behavioral Style Scale Short Form (MBSS-SF) was employed to determine “monitoring processing style”; this concept reflects cognitive and affective characteristics displayed by individuals when facing health threats, such as a cancer diagnosis (Miller, 1987). The Miller Behavioral Style Scale/Monitoring Blunting Style Scale (MBSS), developed to identify differences in information processing styles, has been incorporated as an outcome in a number of cancer studies (Tercyak, 2001; Sheehan 2007; Shiloh, 2008; Cowan, 2008; Kelly, 2011; Meyer, 2007). The MBSS is a 32-item measure that surveys respondents’ coping with four stressful scenarios using a yes or no response format (Klein, 2009). Four items per scenario describe “monitoring,” or information-seeking, behaviors, and the remaining four describe “blunting” or, information-avoiding behavior, which are used to generate a composite score through subtracting the blunting score from the monitoring score, where higher scores represent higher monitoring (Miller, 1996; Miller, 2005). The scale has been validated (see specific information in Methods).

The MBSS-SF has been previously used in studies addressing cancer-specific health threats. Prior studies suggests that due to low internal reliability of the blunting scale (how respondents avoid threatening information), use of the short form, which

limits items to the monitoring subscale, is preferable (Roussi, 2014) The 16-items of the MBSS-SF include 4 threat scenarios: a visit to the dentist, a terrorist hostage scenario, threat of job loss and a negative experience during a flight. Each of the four items per scenario describes “monitoring,” or information-seeking, behaviors. Respondents are first introduced to a prompt briefly describing each scenario, followed by 4 statements using a yes/no response format, where respondents determine if they would or would not perform the behaviors described on each prompt. One point is awarded for each “yes” response to each of the 16 scenarios, while “no responses” receive 0 points. A score between 0 and 16 is generated by adding all responses to the 4 scenarios. The calculated median score of the sample’s responses is used as cutoff to classify respondents as “high monitoring” (score at or above the median) or “low monitoring (score below the median) (Bartle-Haring, 2008).

3. Cancer Health Literacy: The Cancer Health Literacy short version (CHLT-6) is a 6-item cancer literacy test which accurately identifies individuals with limited cancer health literacy. The CHLT-6 contains four multiple choice questions (three answer choices) and two true or false questions. The six items of the CHLT-6 examine knowledge regarding laboratory measures, cancer stages, testing and treatment with some basic numeracy components. This instrument takes approximately two minutes to administer and score and has shown measurement invariance across gender and racial/ethnic groups. Survey scores range from 0 to 6, with a point awarded for each correct answer to an item. Initial validation of the CHLT-6 supported a two-class classification: limited cancer health literacy respondents (0-4 score) and adequate cancer health literacy respondents (a score of 5 or 6) (Dumenci, 2014).

4. Patient anxiety: The Hospital Anxiety and Depression Scale (HADS) Anxiety is a 14-item questionnaire for the assessment of depression and anxiety in an outpatient setting, widely validated and utilized in cancer patient populations. Items of the HADS are scored on a 4-point scale (0-3 points awarded per item), which provides individual scores ranging from zero to 21 for each of the subscales (anxiety and depression). Individual subscales scores are obtained by adding the points scored for each of the seven items of a subscale. Scores of zero through seven are categorized as normal, eight through ten as suggestive of the presence of anxiety and/or depression, and 11 and above as indicative of the presence of anxiety and/or depression (Mitchell, 2010; Annunziata, 2020; Bjelland, 2002). For the purpose of our study, we utilized the anxiety subscale alone as a measure of this disorder in the patient population. Employing the seven items of the subscale, which is scored independently from the depression subscale, is appropriate based on our focus on anxiety outcomes.

#### ***Statistical analysis***

Research questions 1 and 2 focus on anxiety as the outcome variable, as measured by the HADS-A. Individual scores from this survey were classified under one of the three ordinal categories (normal, suggestive, indicative). Research questions 3 and 4 utilize the median score among the sample to develop a binary outcome variable (high information monitoring v. low information monitoring). Based on such characteristics, we utilized binary regression models to assess the relationships between the seven domains of eHLQ scores (continuous variable) and cancer health literacy (binary variable) on anxiety level. Similarly, we used logistic regression models to assess the relationship between each eHLQ domain and cancer health literacy on the information processing level. Full

likelihood ratio analysis and multicollinearity testing were performed to ensure variables met the assumptions of the logistic regression models: independence of observations, variables are binary and absence of multicollinearity in the variables (Hayes, 2009). Regression analysis models, which generate odd ratios and 95% confidence intervals, were employed to address all research questions for Aim 2. Adjusted models included the following covariates: age, race, ethnicity, gender, and marital status. SPSS version 29 was used to complete all statistical analyses (IBM Corp, 2022).

### ***Summary***

Through the previously described analysis, we are able to determine how two critical types of literacy for cancer patients might impact anxiety levels based on their personal monitoring style: high monitoring, who have an active interest in researching information on the disease, or low monitoring, who are less likely to personally seek for information about their condition. The utilization of adjusted regression models on this analysis is appropriate towards addressing our research questions, and to understand if specific variables might confound these associations.

### **Description of Manuscript 3: Moderation Effects of eHealth Literacy and Cancer Health Literacy in the Relationship Between Information Processing and Patient Anxiety**

**Aim 3:** To assess the moderating effects of the seven domains of eHealth literacy and cancer health literacy between information processing and anxiety.

*Hypothesis 1: The seven domains of eHealth literacy will each show moderating effects between information processing and patient anxiety.*

*Hypothesis 2: Cancer health literacy will show moderating effects between information processing and patient anxiety.*

### ***Study sample***

Aim 3 will use the same cross-sectional data as Aims 1 and 2, collected from oncology patients at Temple University Hospital between June and November 2022.

### ***Survey measures***

The measures included in this assessment will be the same as previously described on the survey measures section for manuscript 2.

### ***Statistical analysis***

For aim 3, moderation analysis followed David Kenny's recommendations on statistical analysis for moderation based on the variables and moderator response scales (Judd, 2001.) Hypothesis 1 assessed the moderation effects of each of the seven eHLQ domains (continuous variables) on information processing (binary variable) and patient anxiety (categorical variable). We assessed an additional model including all 7 domains of the eHLQ to assess the overall interaction effects of eHealth literacy on the relationship between information processing and anxiety. For this purpose, we performed moderation regression analysis to calculate regression coefficients and determined the statistical significance of potential moderator effects. Previous research suggests active information-seeking behavior, like high monitoring, is positively associated to eHealth literacy and educational attainment (Tennant, 2015; Lee, 2021.) Furthermore, high monitoring has been previously associated with increased anxiety (Miller, 1987; Tercyak, 2001). As components of eHealth literacy, we predicted that the seven domains of the

eHLQ will individually show a positive moderating effect between information processing behavior and anxiety level.

In hypothesis 2, we tested the moderating effect of cancer health literacy (binary variable) on the relationship between information monitoring (binary variable) and patient anxiety (categorical variable). To address this, we used linear regression models with interaction terms, which provided coefficients and 95% confidence intervals, and aided in determining the presence of moderating effects of cancer health literacy on the relationship between information seeking and patient anxiety (Aguinis, 2004; Baron, 1986). SPSS version 29 was used to complete all statistical analyses (IBM Corp, 2022.)

### ***Summary***

The final aim of this study addresses the moderating effects eHealth literacy and cancer health literacy can have between health information processing and anxiety in our patient sample. Such analysis allowed us to determine how these types of literacy ameliorate or worsen anxiety based on individual monitoring style. According to David Kenny's work on moderation analysis, moderation regression to calculate regression coefficients is suited to examine the existence of moderating effects based on the instruments included in our survey. Statistically significant results provide new, useful insight on the value of eHealth and cancer health literacy on psychosocial outcomes based on patient's personal desire to independently seek out health information.

### **Conclusion of Introduction**

The study described here, and the following manuscripts present novel contributions to the field of eHealth literacy research. As the first implementation of the eHLQ in a US patient sample, this research helps examine and compare self-reported

eHealth literacy using a validated tool, with theoretical items that can provide further insight into the skills and process measures that are needed for patients to attain adequate eHealth literacy. Evidence of the goodness of fit of the eHLQ under a unidimensional model would support the potential of this measure, which addresses eHealth literacy more comprehensively, compared to older instruments, such as the eHEALS. Finding high inter-item correlations across the 7 domains of this tool might strengthen the case for a more parsimonious tool, of less burden, which might encourage providers to include them in future research. Further, providing concrete evidence that a one latent factor of eHealth Literacy fits the existing domains could simplify the process of scoring and survey interpretation. Finally, a one-factor model might precipitate the development of a definition of eHealth literacy which addresses not just literacy skills, but also patient motivations, sense of control, engagement with technology and the degree to which tools fit the user's needs.

The application of this measure along with the CHLT-6, a tool that is tailored specifically for cancer information, provides a clearer understanding on the adequacy of cancer knowledge of a primarily minority patient sample with lower education levels. Additionally, these skills have not previously been studied in conjunction with information processing styles, which can vary greatly and impact the manner in which patients supplement the information provided by healthcare professionals, and how advantageous this additional information might be with regards to their well-being, operationalized as their anxiety level. As previously discussed, the current research remains scarce on the application of eHealth literacy assessments to determine their association to specific health outcomes. Our inclusion of a patient anxiety measure

intends to provide some additional information in understanding this relationship.

Furthermore, evaluating these relationships attempts to underscore some of the obstacles that persist towards the successful implementation and adoption of eHealth technology, particularly in communities that lack access to education and financial resources that are critical for this approach to enhance the access and quality of care of cancer patients.

## **Chapter 2: Manuscript 1**

### **Confirmatory Factor Analysis of the eHealth Literacy Questionnaire (eHLQ) in a US Patient Population: Assessment of a One-Factor Model**

#### **Introduction**

The development and implementation of Internet-driven health technology has significantly expanded over the past 15 years, with a growing number of funded research studies tackling topics from platform and algorithm development to clinical use and patient education (Chen, 2018). eHealth literacy, defined as the “...ability of individuals to seek, find, understand, and appraise health information from electronic resources and apply such knowledge to addressing or solving a health problem”, is considered a foundational skill towards the proper implementation of such innovations in the healthcare setting (Stellefson, 2019). Possessing adequate eHealth literacy is particularly meaningful for individuals who require frequent healthcare services, including older adults and those managing chronic disease (Holman, 2020; Kim, 2020). And will continue to be increasingly important with the widespread adoption of electronic healthcare, portal use, and other digital technologies are incorporated into healthcare (Mackey, 2019).

Growing research provides some insight on the factors that lead to poor eHealth literacy. Cross-sectional data from the 2020 CALSPEAKS survey determined that among California residents 65 and older, education, Internet use frequency and variety of Internet tasks performed were strong predictors of eHealth literacy (Berkowsky, 2021). An interview study in adults 55 and older reports similar results: Internet use, number of devices, and health knowledge were associated with higher eHealth literacy (Arcury,

2020). A study of Internet use and eHealth literacy among baby boomers concluded that use of social media and online health sources, higher educational attainment and use of more electronic devices was also significantly associated to higher eHealth literacy (Tennant, 2015).

While studies focusing on eHealth literacy in ethnic-minority populations remain scant, a recent study among Spanish-speaking, Latino participants found similar relationships between eHealth literacy, education and seeking online health information. Importantly, 62% of participants had not received a high school diploma, and 71% stated they did not seek online health information (Chavarria, 2022), indicating an inverse relationship with eHealth literacy. Older age has also been inversely associated with eHealth literacy and skills using a computer. Older adults, who are increasingly likely to experience chronic illness and/or disability, tend to display lower eHealth literacy and computer experience. Compared to those with adequate health literacy (31.9%), only 9.7% of older adults with low health literacy used the Internet as a health information resource (Levy, 2015).

As the number of Internet-based health tools expands, so has the need to specifically assess eHealth literacy on its own so that measures adequately capture how individuals navigate changing technology. A systematic review from Lee and colleagues identified 7 eHealth literacy instruments in the 41 articles meeting inclusion criteria (Lee, 2021). The eHEALS, developed by Norman (Norman 2006), was evaluated under its validated one-factor structure, as well as a two- and three-factor structure, the latter showing highest internal consistency, cross-cultural and known-groups validity (Paige, 2018 Paige, 2019). However, this widely used tool suffers from its limited assessment of the complexity of

eHealth literacy and does not reflect the role of social media and other technology use as part of the web 2.0 era (Tennant, 2015). Other second era instruments, including the electronic health literacy scale (e-HLS), digital health literacy instrument (DHLI), eHealth literacy assessment toolkit (eHLA) and transactional eHealth literacy instrument (TeHLI), while more comprehensive, have not been extensively evaluated (Seçkin, 2016; van der Vaart, 2017; Karnoe, 2018; Paige, 2019). The Electronic Health Literacy Questionnaire (eHLQ), another identified measure, also is more inclusive of different eHealth skills and has been evaluated. This review suggests that unlike the e-HLS, DHLI and eHLA, the eHLQ shows evidence of structural validity (Lee, 2021). Furthermore, compared to the TeHLI, the eHLQ has been implemented as both a web-based and paper survey; this is an important feature, due to the potential of selection bias when administering an eHealth literacy instrument only available online (Paige, 2019).

The eHealth Literacy Framework (eHLF) published by Kushniruk and colleagues in 2012, contends that within the context of healthcare, user-specific and task-specific dimensions must be measured to adequately characterize eHealth literacy (Kushniruk, 2012). This theoretical framework provided the foundation for the eHLQ, a 35-item measure that assesses seven dimensions found within the healthcare-, user- and task-context in the eHLF model: (1) ability to process information, (2) engagement in own health, (3) ability to engage with digital services, (4) feeling safe and in control, (5) motivation to engage with digital services, (6) access to digital services that work, and (7) digital services that suit individual needs. Initial validation and factor analysis of the eHLQ on a Danish population (n=475) concluded that confirmatory factor analysis supported a 7-factor model for the eHLQ. Scale reliability ranged between  $\alpha = 0.77$  for

scales 2 and 6 and  $\alpha=0.86$  for scales 3 and 4. Though analysis suggests high interfactor correlations between domains 1 and 5, and 6 and 7, researchers preserved all 7 domains due to what they perceived as differences in content (Kayser, 2018). A 2021 validation study in a sample of Australian respondents (n=525) using Bayesian confirmatory analysis supported Kayser's seven-factor model for the eHLQ, stating no significant cross-loading was observed across the 7 factors (Cheng, 2021). However, a salient issue in the application of the eHLQ is it has not been widely tested and has been used in largely homogenous populations in Europe and Australia who were Caucasian and had higher education and literacy.

To our knowledge, the current paper provides the first assessment of the eHLQ in cancer patients in the United States, in a primarily racial minority population with lower education and literacy. Thus, the aim of the current study is to assess if the 7 scales of the eHLQ will fit a more parsimonious model, specifically, a one-factor structure, using confirmatory factor analysis. While previous validation supports a 7-factor structure, a unidimensional model would result in several advantages for the eHLQ. Strong loading factors in a unidimensional scale would indicate that the eHLQ domains are meaningful components in determining differences in eHealth literacy. Further, a single-factor structure would simplify the interpretation of eHLQ results and allow for the development of one cohesive definition of eHealth literacy. A unidimensional eHLQ model would also benefit future researchers wishing to include this measure in research studies, providing a validated, more comprehensive alternative to instruments currently available.

## **Methods**

### ***Participant recruitment and survey administration***

A cross-sectional study was conducted in the oncology department at Temple University Hospital in Philadelphia, PA (Temple University Hospital, 2019). This site was selected as it represents a catchment area for many underrepresented patients, who are more likely to lack educational and technological resources and are vastly different socioeconomically to the prior respondent samples. Inclusion criteria to participate included being 18 years or older, have a self-reported active cancer diagnosis, and was in the process of receiving treatment or follow-up treatment for their cancer. Participants unable to read or understand the English version of the survey packet were excluded from the study. For our purposes, active cancer was defined as "...not received potentially curative treatment, or when there is evidence that treatment has not been curative (e.g., recurrent, or progressive disease)" (Kearon, 2016). The study was approved by the Temple University Institutional Review Board and deemed exempt (protocol number: 29400).

Data was collected between June and September 2022. The investigator and three research assistants were responsible for data collection. Prior to recruitment research assistants received training on approaching potential participants, obtaining patient consent, and assisting with survey administration. Prior to enrollment, staff would verify inclusion criteria, provide verbal consent for participation, and give the respondent the opportunity to read or hear information on confidentiality, risks, benefits, and compensation. Hard copies of the consent were available for the participant to take with them. All surveys were administered as paper copies, and completed by the participant

while they were waiting to see the doctor or before chemotherapy. They were also given the option to complete the survey with the assistance of a research assistant, to accommodate for visual/hearing limitations and literacy. Surveys took approximately 15 minutes to complete. All participants who completed the survey were provided with a \$15 gift card to a local store.

### ***Measures***

**Demographic characteristics.** Participants demographic characteristics assessed included age, highest level of education completed, type of insurance patient had, race, Hispanic/Latinx ethnicity, annual household income, gender, marital status, was this their first cancer diagnosis, type of cancer (primary site) of their diagnosis and current cancer stage.

**eHealth Literacy Questionnaire (eHLQ).** Developed by Kayser and colleagues (2018), the eHLQ is a 35-item measure that uses 4-point Likert response scale (strongly disagree, disagree, agree, strongly agree) with 4 to 6 items for each of the seven eHealth literacy domains: (1) ability to process information (5 items), (2) engagement in own health (5 items), (3) ability to engage with digital services (5 items), (4) feeling safe and in control (5 items), (5) motivation to engage with digitals services (5 items), (6) access to digital services that work (6 items), and (7) digital services that suit individual needs (4 items). Definitions for each of the domains are included in Appendix 1. Scoring guidelines for the eHLQ state that each domain is independently scored to generate a mean score, ranging between 1 and 4; all items are weighted equally (Kayser, 2018) and for all scales a higher score indicates greater eHealth literacy (Cheng, 2021).

### ***Data Analysis***

Data collected from the eHLQ was entered and scored using a pre-programmed algorithm provided alongside the questionnaire by the Swinburne University of Technology in Melbourne, Australia (Cheng, 2021). A user agreement was completed, and use of the measure was approved for the study. The Microsoft Excel scoring worksheet calculated mean scores and standard deviation for each of the seven domains, as well as a total score for each domain for each respondent (No author, 2022).

Principal Component Analysis using Varimax rotation was performed using SPSS version 29.0 (IBM, 2022). Descriptive statistics were calculated for sociodemographic characteristics of the study participants. A correlation matrix was used to determine significant inter-item correlations among the factors, while the Kaiser-Meyer-Olkin value (KMO) and Bartlett's Test of Sphericity were employed to test if all correlations were significantly different from zero (Kim, 2008; Stehlik-Barry, 2017). Determination of the number of factors to be extracted employed a scree plot, which allows to visually assess the number of components with more than 1 Eigenvalue and component extraction variance output, which provide specific values from each component. The number of components retained must have an Eigenvalue greater than one (Johnstone, 2001; Braeken, 2017).

MPlus was used to determine the fitness of a unidimensional factor model (Muthén & Muthén, 2017). Model fit was assessed through the Chi-square index of fitness, comparative fit index (CFI), the Lewis-Tucker index (TLI) and Root Mean Square Error of Approximation (RMSEA) (Hu, 1999; Kenny, 2015). Index cutoffs for fitness assessment of the latent model included a CFI score equal to or above 0.95, a TLI

score equal to or above 0.95, and a RMSEA score equal to or below 0.07 (Xia, 2019). Due to a smaller sample size and the assumption of non-normality of the data distribution, both the Maximum Likelihood parameter (MLM) and the Mean- and Variance-Adjusted Maximum Likelihood (MVML) estimator were employed in testing this model. Finally, Cronbach's  $\alpha$  value of 0.9 or greater, and McDonald's  $\Omega$  value of 0.8 or higher were used to determine the items' internal validity (Muthén & Muthén, 2017; Maydeu-Olivares, 2017).

## **Results**

Responses for 153 participants were collected for analysis (Table 1). The mean age of participants was 62.3 (SD 11.0) years, with 45.7% 65 years or older. Sixty-three point four percent were women, 74.1% were Black/African American, 16.7% were Hispanic/Latinx, and 45.4% reported having graduated from high school. Of those who reported household income, 73.2% earned less than \$25,000 a year. Over two-thirds (68.4%) identified Medicare and/or Medicaid as their form of insurance and for most this was their first cancer diagnosis (74.2%). Additionally, about a third of respondents were either unsure or failed to complete information on their cancer stage (32.7%). Mean and standard deviation for the seven eHLQ domains, scored from 1 to 4, ranged between 2.86 (SD 0.57) for domain three, "ability to actively engage with digital services," to 3.10 (SD 0.42) for domain two, "understanding of health concepts and language" (Table 2).

Validation analysis was done on 152 respondents; one survey was not included in analysis due to missing values that prevented scoring. The inter-item correlation matrix in Table 3 displays the correlations between eHLQ domains. All inter-item correlations were statistically significant at a  $p < 0.001$ , with Pearson correlation coefficients ranging

from 0.582 between factors 3 and 4, and 3 and 6 (lowest correlation) to 0.817 between factors 1 and 5 (highest correlation). A score of 0.901 on the Kaiser-Meyer-Olkin (KMO) measure suggests the sample was adequate for this analysis, while the Bartlett's Test of sphericity was statistically significant at  $p < 0.01$ , with a Chi-square value of 794.010, supporting the inter-item correlations. Based on the criteria of extraction of components with Eigenvalues greater than 1, only one-component was extracted. The one-component extraction, with an Eigenvalue of 4.98, accounted for 71.1% of the variance. Visual examination of the Scree plot confirmed the one-component retention, with all other components presenting Eigenvalues less than one.

Table 4 includes results of the fit indices of a one-factor model for the eHLQ using MLM and MLMV to calculate fit indices. In both assessments, the Chi-square model of fitness (MLM  $\chi^2 = 34.069$ ,  $p < 0.002$ ; MLMV  $\chi^2 = 30.397$ ,  $p < 0.007$ ) indicates a one-factor model does not fit the eHLQ observed variables. RMSEA scores using both estimates suggest this model shows marginal fitness (MLM RMSEA = 0.097 [0.056-0.139]; MLMV RMSEA = 0.088 [0.044-0.131]). However, the MLM RMSEA was statistically significant at  $p = 0.032$ . CFI (MLM = 0.964; MLMV = 0.963) and TLI values (MLM = 0.946; MLMV = 0.944) were closest to meeting the cutoff criteria, suggesting a one-factor model for the eHLQ to be acceptable. Figure 1. Displays the standardized factor loadings and standard error values for the eHLQ as a unidimensional model. The factor loadings for the 7 domains of the eHLQ show a strong association to the latent factor, eHLQ, set to 1.0 These factor loadings ranged between 0.764 (SE 0.047) for domain 4 and 0.874 (SE 0.026) for domain 5. Internal consistency of the eHLQ items

supported the one-factor model, with a Cronbach's  $\alpha= 0.93$  and a McDonald's  $\Omega= 0.93$ , both scores which indicate high reliability.

<b>Overall</b>	<b>n= 153 (100%)</b>
<b>Characteristics</b>	
<b>Age at survey</b>	<b>n= 151</b>
18-44	11(7.3)
45-54	16 (10.6)
55-64	55 (36.4)
65-74	54 (35.8)
75+	15 (9.9)
<b>Gender</b>	<b>n= 153</b>
Male	54 (35.3)
Female	97 (63.4)
Other	1 (0.7)
<b>Race</b>	<b>n=143</b>
White	21 (14.7)
Black	106 (74.1)
Other	16 (11.2)
<b>Hispanic</b>	<b>n=150</b>
Yes	25 (16.7)
No	125 (83.3)
<b>Education</b>	<b>n= 152</b>
Less than high school	31 (20.4)
High school diploma/GED	69 (45.4)
Some college/vocational school	29 (19.1)
College graduate or higher	23 (15.1)
<b>Income</b>	<b>n=112</b>
Less than \$10,000-\$25,000	82 (73.2)
\$25,001-\$50,000	17 (15.2)
\$50,001-\$75,000	6 (5.4)
\$75,001 or greater	7 (6.3)
<b>Insurance</b>	<b>n= 136</b>
Private	31 (22.8)
Medicare/Medicaid	93 (68.4)
Unsure/Other	12 (8.8)
<b>Marital status</b>	<b>n= 151</b>
Married	33 (21.9)
Single	81 (53.6)
Divorced	24 (15.9)
Widowed	13 (8.6)
<b>First cancer diagnosis</b>	<b>n= 151</b>
Yes	112 (74.2)
No	39 (25.8)

Table 1. Demographic characteristics of patient respondents

Cancer stage	n= 153
1	33 (21.6)
2	18 (11.8)
3	18 (11.8)
4	34 (22.2)
Unsure/Missing	50 (32.7)

Table 1 continued. Demographic characteristics of patient respondents

Scale	Mean (SD)
1. Using technology to process health information	2.87 (0.55)
2. Understanding of health concepts and language	3.10 (0.42)
3. Ability to actively engage with digital services	2.86 (0.57)
4. Feel safe and in control	2.99 (0.51)
5. Motivated to engage with digital services	2.97 (0.50)
6. Access to digital services that work	3.02 (0.43)
7. Digital services that suit individual needs	2.87(0.53)

Table 2. Mean scores for the eHealth Literacy Questionnaire (n=152)

Domain	1	2	3	4	5	6	7
1	1	.676*	.736*	.588*	.817*	.675*	.678*
2	.676*	1	.592*	.623*	.684*	.684*	.606*
3	.736*	.592*	1	.582*	.622*	.582*	.653*
4	.588*	.623*	.582*	1	.659*	.663*	.696*
5	.817*	.684*	.622*	.659*	1	.677*	.709*
6	.675*	.684*	.582*	.663*	.677*	1	.700*
7	.678*	.606*	.653*	.696*	.709*	.700*	1

\*Pearson  $\chi^2$  correlation is significant at  $p < 0.001$ .

Table 3. Inter-item correlation matrix for the 7 scales of the eHLQ (n=152)

	MLM	MLMV
<i>n</i>	152	152
$\chi^2$	34.069	30.397
<i>df</i>	14	14
<i>p</i>	0.002	0.007
<b>RMSEA (90% C.I.)</b>	0.097 (0.056-0.139)	0.088 (0.044-0.131)
<i>p</i>	0.032	0.071
<b>CFI</b>	0.964	0.963
<b>TLI</b>	0.946	0.944

Table 4. Model fit indices for unidimensional eHLQ structure

Domain	Description	Factor Loading (SE)
1	Using technology to process health information	0.872 (0.027)
2	Understanding of health concepts and language	0.785 (0.038)
3	Ability to actively engage with digital services	0.768 (0.027)
4	Feel safe and in control	0.764 (0.047)
5	Motivated to engage with digital services	0.874 (0.026)
6	Access to digital services that work	0.807 (0.044)
7	Digital services that suit individual needs	0.821 (0.039)

Table 5. Factor loadings of the 7 scales of the eHealth Literacy Questionnaire

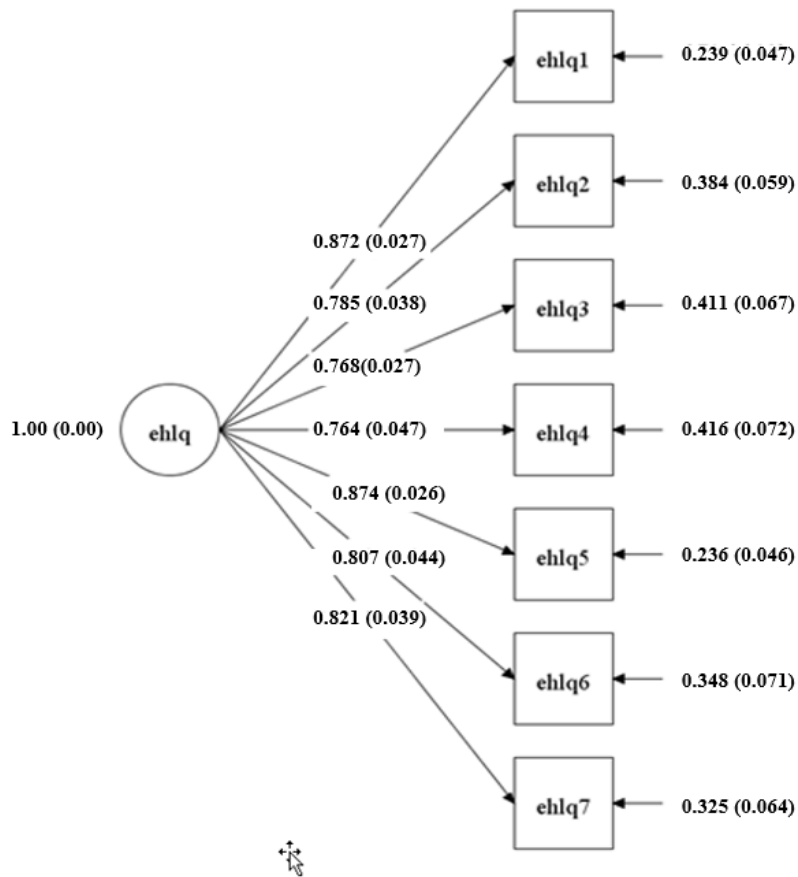


Figure 1. eHLQ standardized one-factor model with factor loadings and residual errors (n= 152)

## Discussion

The current study used confirmatory factor analysis to assess the fitness of a one-factor model of the eHLQ in a patient subgroup not previously tested using this measure. Although the initial validation by Kayser and colleagues supported a 7-factor model, our findings suggest that, with our patient sample, a unidimensional structure might be feasible. This has important implications for the future use of the eHLQ (Kayser, 2018). Our sample population, while not representative of the overall US cancer patient population, oversamples groups that are often underrepresented in research studies (Singh, 2017), namely racial and ethnic minorities. There were two primary factors that we took into account for focusing on this group: this patient sample was starkly different across major socioeconomic factors compared to previously tested groups, and due to the existing disparities in resources in this community, there is a high likelihood that individuals such as those included in this study are more likely to experience low eHealth literacy and benefit from evidence-based interventions (Chesser, 2016; Li, 2018).

The analysis of inter-item correlations in our study is meaningful as it points to some similarities in how highly correlated the domains are, as previously observed by Kayser and colleagues. In their discussion, the authors argue that while correlations  $r=0.95$  (domains 1 and 5) and  $r=0.96$  (domains 6 and 7) are quite high, content differentiation and possible causal associations justify a less parsimonious model (Kayser, 2018). While our analysis shows slightly lower inter-item correlations for these domain pairs ( $r=0.82$  for domains 1 and 5;  $r=0.70$  for domains 6 and 7), all these correlations were statistically significant and all scores exceeded 0.5, commonly used as the high-end threshold for good correlation values (Clark, 2019). Such findings suggest

that there is some potential redundancy between the domains and likely between the items. With 35 items, the eHLQ could be considered a high burden instrument, particularly if used along other measures. Future research into potential item reduction of the survey would thus be useful to determine if a shorter measure can sustain the high internal validity observed in our findings. This would make measuring eHealth literacy not only easier, but potentially assist healthcare providers in screening patient populations to strategize how to assist patients with skills that may require technology skills, such as using patient portals.

It should be noted, however, that the indices of fitness employed in examining the unidimensional eHLQ model provide some conflicting results. Using both the MLM and MLMV estimators to adjust for our smaller, not normally distributed sample resulted in similar scores for each of the fit indices included. Although the Chi-square test of fitness did not support a one-factor model for the eHLQ, this test is known to be impacted by smaller sample sizes and strong correlations; in this case, such limitations of the test make the results difficult to interpret (Hu, 1998). Additionally, the MLM RMSEA value at 0.097 (0.056-0.139), suggests this model is of marginal fitness and has a broader than desired confidence interval (Fabrigar, 1999). However, the CFI and TLI indices of fitness, which are more stable to sample size differences, do support a one-factor model for the eHLQ. Based on these findings, future assessments with larger, more diverse samples are necessary to ensure a one-factor eHLQ model is appropriate and useful.

Our study has some limitations. While our sample population provides useful information on groups often underrepresented in research studies, the use of a convenience sample implies that our results do not represent the overall cancer patient

population of the United States. Thus, findings that suggest this unidimensional structure may not be supported in these larger samples. Furthermore, our limited sample size has the potential to impact some of the analysis and had to be accounted for in selecting the model estimation parameters. Lastly, in conducting our analysis, we restricted our analysis to the 7-domain level; such findings might be unable to reflect item-level errors, which warrant further examination with a larger number of respondents.

### **Conclusion**

eHealth literacy is likely to play a growing role in healthcare settings as patient-driven needs grow under limited human resources for care. Assessing the viability of a unidimensional eHLQ model serves two interrelated purposes. First, evidence of intercorrelation and adequate fit of all domains of the eHLQ under one factor underscores the value of these different characteristics in a more comprehensive operationalization of eHealth literacy. Such a description thus reflects the importance of an individual's motivation, sense of safety, and control and engagement with health and technology, and not solely their perceived skillset using and operating health technology. Second, assessing high correlations between and within the scales might allow for the development of a short version of the eHLQ from its initial 35 items. The availability of a short form could allow for more widespread use of the eHLQ, while a one-factor, single-score model would facilitate interpretation of results and application of findings towards reducing the gap in eHealth literacy disparities.

<b>Domain</b>	<b>Definition</b>
1. Ability to process information	Able to read, write and remember, apply basic numerical concepts, and understand context-specific language (e.g., health, IT or English) as well as critically appraise information. Know when, how and what information to use.
2. Engagement in own health	Know about basic physiological functions and own current health status. Aware of risk factors and how to avoid them or reduce their influence on own health as well as navigating the health care system.
3. Ability to actively engage with digital services	Being comfortable using digital services for handling information.
4. Feel safe and in control	Feel that you have the ownership of personal data stored in the systems and that the data are safe and can be accessed only by people to whom they are relevant (own doctor, own nurse, etc.).
5. Motivated to engage with digital services	Feel that engaging in the use of digital services will be useful for them in managing their health.
6. Access to digital services that work	Have access to digital services that the users trust to be working when they need it and as they expect it to work.
7. Digital services that suit individual needs	Have access to digital services that suit the specific needs and preferences of the users. This includes responsive features of both IT and the health care system (including careers) as well as adaptation of devices and interfaces to be used by people with physical and mental disabilities.

Appendix 1 The 7 constructs of the eHealth Literacy Questionnaire (from Kaiser, 2018, Multimedia Appendix 2)

## **Chapter 3: Manuscript 2**

### **eHealth and Cancer Health Literacy in an Urban Cancer Patient Population:**

#### **Associations with Information Processing Style and Patient-Reported**

#### **Anxiety**

#### **Introduction**

The journey through a cancer diagnosis and its treatment and management compels patients to learn and understand complex medical information and terminology that are seldom utilized outside of the healthcare field. Proficiency in understanding these terms is particularly important to motivate shared decision-making between patients and providers, and support self-management of care, using healthcare technology tools (Cooley, 2017). But health literacy, defined as the capacity to obtain, process, and understand basic health information (Parker, 2010), and cancer health literacy, which is domain specific literacy for those with cancer (Dumenci, 2014), can impact how patients process information, their personal perspectives and motivations that support their health decision-making, and ultimately the quality of their treatment, management, and health outcomes (Holden, 2021). A recent mixed-methods study by Holden and colleagues on the impact of health literacy in cancer care found that across quantitative and qualitative studies, individuals with greater health literacy were more actively engaged in their care experiences and reported better quality of life compared to those with low health literacy (Holden, 2021).

A related and increasingly important skill is electronic or digital literacy (eHealth), defined as the ability to seek, find, understand, and appraise health information from electronic sources (Norman, 2006). This is also important as the use of the internet

for health information and proliferation of health portals offered by healthcare institutions continue to increase. Adequate eHealth/digital health literacy is also important specifically for cancer patients, as many health information sources depend on accessing and using Internet-driven tools (Cooley, 2017). Nevertheless, older adults, who are at increased risk of cancer, those who report low Internet proficiency, and those with lower socioeconomic status are most likely to have inadequate eHealth literacy (Parker, 2022; Jacobs, 2016; Latulippe, 2017; Leader, 2021), indicating disparities may impact the ability of vulnerable patients to participate fully in medical decision making and may affect how patients react to their diagnosis and treatment.

Increased emotional distress and anxiety are common following a cancer diagnosis and can impact patients along the cancer continuum. A study on cancer-related distress in the US and Canada found 46% of patients experience clinically significant levels of distress; this is especially true in pancreatic and lung cancer patients (Carlson, 2019). Among cancer survivors, anxiety can become a persistent obstacle; a systematic review estimated that between 45 and 48% of patients reported experienced symptoms of anxiety 1 to 2 years post-treatment (Harrington, 2010). Cancer outcomes have also been linked to psychological disorders. A meta-analysis by Wang and colleagues found that anxiety and depression were associated with an increased relative risk for cancer-specific and all-cause mortality (Wang, 2020). An analysis of physical and mental quality of life among older cancer patients using results from the Medicare Health Outcomes Survey (MHOS) found that compared to those without cancer, individuals with a lung, bladder, breast, colorectal or Non-Hodgkins Lymphoma diagnosis reported lower mental quality of life (Smith, 2008). The prevalence and impact of anxiety at different stages of the

cancer continuum underline the importance of addressing possible cognitive and behavioral factors that might contribute to psychological comorbidities in cancer, and whether these factors have an association with eHealth literacy, a previously untested relationship.

One factor that has been shown to increase anxiety in cancer patients is information processing style, which characterizes how an individual prefers to seek or avoid information, usually with respect to a perceived threat (Miller, 2015). In the case of a cancer diagnosis, these specific profiles might be relevant towards determining the willingness, motivation, and sense of worry, among other factors, that might influence the patient's engagement with eHealth, and thus their potential to improve their eHealth literacy. Miller's 1987 work on information processing styles describes two main profiles: monitors, who actively look for information in threatening scenarios, and blunters, who cope through avoidance of information under such circumstances, each with advantageous and disadvantageous characteristics (Miller, 1987). In a medical scenario, such as diagnosis or treatment of cancer, monitors have been found to be more likely to ask questions from medical providers, engage in decision-making, and think about the consequences of medical decisions (Timmermans, 2007; Wakefield, 2007). However, monitors are also more likely than blunters to experience decisional regret, exhibit less satisfaction with health information, and are more likely to suffer from affective outcomes such as anxiety (Mellon, 2008; Roussi, 2014). In contrast, blunters or low monitors often decline health information resources and seek escape mechanisms and distraction as a way of managing potential distress in a threatening situation (van Zuuren, 1991). Nevertheless, blunters are also less likely to exhibit anxiety, depression or worry

in clinical situations, and express higher satisfaction in some scenarios, such as a cancer genetic counseling session (Nordin, 2002; Plamann, 2021).

While information processing style and mental health outcomes in cancer have been previously examined in the literature, the impact of eHealth literacy and cancer-specific literacy on these factors is unknown. Higher eHealth and cancer literacy are useful skills, particularly for individuals who exhibit greater health information-seeking patterns. Yet, as previously mentioned, such high monitoring profiles can negatively impact the mental health of patients (Plamman, 2021). Thus, the overall aim of this study is to examine the relationships between eHealth literacy and cancer health literacy to information processing style (high v. low monitoring) and patient anxiety. For this purpose, we focused our analysis on addressing the following questions:

**Research question 1:** Is there an association between eHealth Literacy and higher anxiety in cancer patients?

**Research question 2:** Is there an association between eHealth Literacy and higher information processing (monitoring) in cancer patients?

**Research question 3:** Is there an association between cancer health literacy and higher information processing (monitoring) in cancer patients?

**Research question 4:** Is there an association between cancer health literacy and higher anxiety in cancer patients?

To our knowledge, our study is the first to provide insight into the relationships between cancer-specific literacy, eHealth literacy, anxiety, and information processing.

Thus, our findings contribute novel information on the relationships among these

variables, adding to understanding of the importance of literacy, patient outcomes, and patient behaviors in people with cancer.

## **Methods**

### ***Participant recruitment and survey administration***

Patient recruitment for this cross-sectional study was completed in the oncology department at Temple University Hospital (TUH) in Philadelphia, PA. TUH provides an appropriate catchment area for underserved cancer patients. Such patients are more likely to have less educational and technological resources and lower socioeconomically characteristics compared to previous population samples, all risks for lower health and eHealth literacy, and ensuring an adequate number of patients. Participant inclusion criteria included: being 18 years or older, self-reporting an active cancer diagnosis, and currently receiving treatment or follow-up for their cancer. Individuals who were unable to read or understand English were excluded from the study. For the purposes of the inclusion criteria, active cancer was defined as "...not received potentially curative treatment, or when there is evidence that treatment has not been curative" (e.g., recurrent, or progressive disease) (Kearon, 2016). This study was approved by the Temple University Institutional Review Board and deemed exempt (protocol number: 29400).

Survey data collection occurred between June and September 2022. Prior to the beginning of patient recruitment, study staff received training on how to approach potential participants, obtaining patient consent, and assisting with survey administration when needed. Before participant enrollment, survey administrators would verify inclusion criteria, receive verbal consent for participation, and provide the respondent the necessary time to read or hear information on confidentiality, risks, benefits, and

compensation. Hard copies of the consent information were available for participants to take with them, if desired. All surveys were administered as paper copies and completed by participants while waiting for their doctor's appointments or treatment. Respondents were also given the option to complete the survey with the assistance of a research assistant, to accommodate visual/hearing limitations and literacy. Surveys took 15 minutes to complete on average. All participants who completed the survey were provided with a \$15 gift card to a local store.

### *Survey Measures*

**Demographic Characteristics.** The survey included items measuring demographic information, which included: age, highest level of education completed, type of health insurance, race, Hispanic/Latinx ethnicity, annual household income, gender, marital status, whether this was their first cancer diagnosis, type of cancer (primary site) of their diagnosis, and current cancer stage.

**eHealth Literacy.** eHealth literacy was measured using the eHealth Literacy Questionnaire (eHLQ). Developed by Kayser (2018), the eHLQ is a 35-item questionnaire using a 4-point Likert response scale from strongly disagree to strongly agree. The measure is composed of seven domains, with each of the domains containing between 4 and 6 items: (1) ability to process information (5 items,  $\alpha= 0.84$ ), (2) engagement in own health (5 items,  $\alpha= 0.77$ ), (3) ability to engage with digital services (5 items,  $\alpha= 0.86$ ), (4) feeling safe and in control (5 items,  $\alpha= 0.86$ ), (5) motivation to engage with digital services (5 items,  $\alpha= 0.85$ ), (6) access to digital services that work (6 items,  $\alpha= 0.77$ ), and (7) digital services that suit individual needs (4 items,  $\alpha= 0.85$ ) (Kayser, 2018). Each domain of the eHLQ is scored independently to generate a mean

score, ranging between 1 and 4, with all items within the domain weighted equally (Kayser, 2018). Increasing scores in each domain indicate higher eHealth literacy for that scale. The final eHLQ results provide seven scores, which are reported separately (Kayser, 2018).

**Information Processing.** The Miller Behavioral Style Scale Short Form (MBSS-SF) was used to assess “monitoring processing style.” Developed by Miller (1987), monitoring style reflects cognitive and affective characteristics individuals might present when they encounter a threat; in the case of our study the health threat is the existing cancer diagnosis (Miller, 1987). This short form measures specifically monitoring behavior (Roussi, 2014), and is composed of 16 items, with four items included for four different threat scenarios: a visit to the dentist, a terrorist hostage event, potential loss of employment, and being in a flight experiencing heavy turbulence. The traditional form of the MBSS has previously shown issues with internal validity ( $\alpha = 0.56-0.64$ ); however, limiting the scale to the monitoring subscale has improved reliability ( $\alpha = 0.74$ ) (Bartle-Haring, 2008). For every scenario, a short prompt describing the event is provided, followed by four statements where respondents state whether they would or would not perform the behaviors described by each statement (yes or no). A cumulative score between 0 and 16 is calculated, with each “yes” response receiving 1 point, and each “no” response receiving no points. The median score among all respondents is calculated and used as the cutoff point between “high monitoring” individuals (scores at or above the median) and “low monitoring” individuals (scores below the median) (Bartle-Haring, 2008).

**Cancer Health Literacy.** The Cancer Health Literacy short version (CHLT-6) measure is used to identify individuals with limited cancer health literacy (Dumenci, 2014). The 6-item test includes four multiple choice questions (3 answer choices) and two true or false questions. Items in the CHLT-6 examine various aspects of knowledge related to cancer diagnosis and treatment, such as laboratory measures, cancer staging, testing and treatment, as well as some basic numeracy. The CHLT-6 is a low burden measure, taking about 2 minutes to administer and score. This tool also has a high degree of precision, displaying large differences in probability of accurate responses to the 6 items between those with limited and adequate cancer health literacy. Scores can range from 0 to 6, where a point is awarded for each correct answer. Initial validation of the CHLT-6 supported a dichotomous classification of results. Respondents are said to present limited cancer health literacy if they score between 0 and 4, or adequate cancer health literacy if they score a 5 or 6 (Dumenci, 2014).

**Patient Anxiety.** The Hospital Anxiety and Depression Scale (HADS) is a 14-item questionnaire developed to examine depression and anxiety in an outpatient setting (Zigmond, 1983). This instrument has been widely validated and utilized in cancer patient populations (Mitchell, 2010). Due to the focus of this study, we have employed only the anxiety subscale as a measure of this disorder in the patient population. The 7-item anxiety subscale can be used independently from the depression subscale as each is scored independently (Annunziata, 2020; Muzzatti, 2022). Internal validity for the HADS-A subscale ranges between  $\alpha = 0.67-0.90$ , with a mean of 0.82 (Skapinakis, 2014). HADS items are scored using a four-point scale, ranging from 0 to four. Scores for the HADS-A range between 0 and 21, through addition of the points from each of the 7 items

in the subscale. A respondent score is categorized under one of three classifications: normal (scores 0 through 7), borderline abnormal (scores 8 through 10) or abnormal (scores 11 through 21) (Mitchell, 2010; Annunziata, 2020; Bjelland, 2002.) For the purposes of the following analysis, borderline abnormal and abnormal categories were combined to produce a binary HADS-A score categorization.

### *Statistical Analysis*

Pearson Chi-square tests and one-way analysis of variance tests (ANOVA) were used to examine significant differences between the variables of interest and demographic characteristics previously listed. To address research questions 1 through 4, binary regression models were conducted, to assess the relationship of the seven domains of the eHLQ or cancer health literacy and patient anxiety or information processing. Regression analysis was used to calculate odd ratios, 95% confidence intervals and statistical significance ( $p < 0.05$ ). (Hayes, 2009). Full likelihood ratio analysis and multicollinearity testing were calculated to ensure variables met the assumptions of logistic regression: independence of observations, binary variables, and absence of multicollinearity (Hayes, 2009). Adjusted regression models included the following covariates based on statistically significant differences on outcomes (anxiety, information processing) between-groups: age (64 years and under, 65 years and older), education (less than high school, high school degree or more than high school) and race (White, Black, or Other). SPSS version 28 was used to complete all statistical analyses (IBM Corp, 2021.)

## **Results**

Surveys were collected from 153 eligible cancer patients (Table 1). Mean age of respondents was 62.3 (SD 11.0) years, with just under half (45.7%) being 65 years or more. Respondents were more likely to be women (63.4%), Black (74.1%), and most had completed high school (45.4%). Of those who reported household income (73.2%), over two thirds (73.2%) earned less than \$25,000 a year. Medicare and Medicaid were the most common forms of insurance (68.4%). Almost three fourths of respondents reported this was their first cancer diagnosis (74.2%). When asked about their cancer stage, almost one third of participants responded they did not know or were unsure of their stage at diagnosis (32.7%).

<b>Overall</b>	<b>n= 153 (100%)</b>
<b>Characteristics</b>	
<b>Age at survey</b>	<b>n= 151</b>
18-44	11(7.3)
45-54	16 (10.6)
55-64	55 (36.4)
65-74	54 (35.8)
75+	15 (9.9)
<b>Gender</b>	<b>n= 153</b>
Male	54 (35.3)
Female	97 (63.4)
Other	1 (0.7)
<b>Race</b>	<b>n=143</b>
White	21 (14.7)
Black	106 (74.1)
Other	16 (11.2)
<b>Hispanic</b>	<b>n=150</b>
Yes	25 (16.7)
No	125 (83.3)
<b>Education</b>	<b>n= 152</b>
Less than high school	31 (20.4)
High school diploma/GED	69 (45.4)
Some college/vocational school	29 (19.1)
College graduate or higher	23 (15.1)
<b>Income</b>	<b>n=112</b>
Less than \$10,000-\$25,000	82 (73.2)
\$25,001-\$50,000	17 (15.2)
\$50,001-\$75,000	6 (5.4)
\$75,001 or greater	7 (6.3)
<b>Insurance</b>	<b>n= 136</b>
Private	31 (22.8)
Medicare/Medicaid	93 (68.4)
Unsure/Other	12 (8.8)
<b>Marital status</b>	<b>n= 151</b>
Married	33 (21.9)
Single	81 (53.6)
Divorced	24 (15.9)
Widowed	13 (8.6)
<b>First cancer diagnosis</b>	<b>n= 151</b>
Yes	112 (74.2)
No	39 (25.8)

Table 1. Demographic characteristics of patient respondents

<b>Cancer stage</b>	<b>n= 153</b>
1	33 (21.6)
2	18 (11.8)
3	18 (11.8)
4	34 (22.2)
Unsure/Missing	50 (32.7)

Table 1 continued. Demographic characteristics of patient respondents

Table 2 presents means and standard deviation values for each of the seven domains of the eHLQ (n= 152; range 1-4). No mean overall value is reported as eHLQ scoring does not provide a global score of all domains. The lowest mean scoring scale was domain 3 at 2.86, which assesses the “ability to actively engage with digital services”. Domain two, “engagement in your own health,” had the highest mean domain score at a 3.10.

<b>Domain</b>	<b>Mean (SD)</b>
1. Ability to process information	2.87 (0.55)
2. Engagement in own health	3.10 (0.42)
3. Ability to actively engage with digital services	2.86 (0.57)
4. Feel safe and in control	2.99 (0.51)
5. Motivated to engage with digital services	2.97 (0.50)
6. Access to digital services that work	3.02 (0.43)
7. Digital services that suit individual needs	2.87(0.53)

Table 2. eHLQ domain sample mean scores (n= 152)

Table 3 includes the score classification of respondents for the CHLT-6, HADS Anxiety subscale and MBSS-M. Response rate to the CHLT-6 was 96.7% (n=148), with most participants scoring between 1 and 4, reflecting limited cancer literacy (59.5%). Response rate to the HADS-A was lower, at 88.2% (n=135). In the anxiety scale, most participants were classified as “normal” (63.7%), followed by “abnormal” (23.7%), with “borderline abnormal” having the least results (12.6%). The MBSS-M response rate was 92.8% (n=142), with over half of participants being classified as “low monitors” (56.2%).

Response rate to the eHLQ was highest, with only one survey being excluded from the analysis.

<b>Measures</b>	<b>N (%)</b>
<b>CHLT-6</b>	
Limited	91 (59.5)
Adequate	57 (37.3)
<b>HADS-A</b>	
Normal	86 (63.7)
Borderline	17 (12.6)
Abnormal	32 (23.7)
<b>MBSS-M</b>	
Low monitoring	86 (56.2)
High monitoring	56 (36.6)

Table 3. Cancer health literacy, anxiety, and information processing classification from patient respondents

Bivariate analysis was performed to determine any significant differences across demographic subgroups in the variables of interest. Chi-square tests determined significant differences between individuals 64 years and under and those 65 and older ( $\chi^2= 18.83, p<0.001$ ). Differences in cancer health literacy across highest level of education (less than high school, high school diploma, more than high school) were also significant ( $\chi^2= 25.32, p<0.001$ ). ANOVA tests showed between-group differences in domain 2 of the eHLQ by age ( $F= 5.69, p<0.02$ ), and educational attainment ( $F= 5.53, p=0.01$ ). Domain 3 of the eHLQ showed significant between-group differences by educational attainment ( $F= 4.78, p=0.01$ ). Between- group differences by race (White, Black, Other) were statistically significant in domain 4 ( $F= 3.96, p= 0.02$ ). Lastly, one-sided ANOVA tests found significant between-group differences by age were in domain 6 of the eHLQ ( $F= 7.54, p= 0.01$ ).

Binary regression analysis results, including unadjusted and adjusted odd ratios, for the association between eHLQ domains and anxiety are included in Table 4.

Increasing age was associated with a lower likelihood of scoring as borderline or abnormal on the HADS anxiety measure (OR= 0.19,  $p < 0.001$ ). None of the seven individual eHLQ domains showed significant associations to anxiety scores in our sample. Nevertheless, of the non-significant results, domains 1, 2, 4 and 6 showed an inverse association to increased anxiety, while domains 3, 5 and 7 were positively associated with increased anxiety. Educational attainment and race showed no statistically significant correlations to anxiety scores.

	<b>df</b>	<b>Unadjusted Odds Ratio (95% CI)</b>	<b><i>p</i></b>	<b>Adjusted Odds Ratio (95% CI)</b>	<b><i>p</i></b>
eHLQ 1	1	0.56 (0.16, 1.97)	0.37	0.65 (0.15, 2.83)	0.56
eHLQ 2	1	0.48 (0.13, 1.70)	0.25	0.27 (0.06, 1.26)	0.10
eHLQ 3	1	1.66 (0.63, 4.37)	0.31	2.11 (0.69, 6.50)	0.19
eHLQ 4	1	0.60 (0.21, 1.70)	0.34	0.52 (0.16, 1.75)	0.29
eHLQ 5	1	2.02 (0.53, 7.63)	0.30	2.16 (0.47, 9.88)	0.32
eHLQ 6	1	0.70 (0.19, 2.52)	0.59	0.46 (0.10, 2.06)	0.31
eHLQ 7	1	1.53 (0.51, 4.60)	0.45	2.08 (0.57, 7.66)	0.27
<b>Covariates</b>					
Age	1	-	-	0.19 (0.08, 0.45)	<0.001*
Education (Less than HS)	2	-	-	1.0	0.66
Education (HS diploma)	1	-	-	0.73 (0.26, 2.09)	0.56
Education (More than HS)	1	-	-	0.59 (0.19, 1.85)	0.37
Race (White)	2	-	-	1.0	0.54
Race (Black)	1	-	-	1.58 (0.50, 4.99)	0.44
Race (Other)	1	-	-	0.85 (0.16, 4.39)	0.85

p<0.05\*; eHLQ 1: Ability to process information; eHLQ 2: Engagement in own health; eHLQ 3: Ability to actively engage with digital services; eHLQ 4: Feel safe and in control; eHLQ 5: Motivated to engage with digital services; eHLQ 6: Access to digital services that work; eHLQ 7: Digital services that suit individual needs.

Table 4. Odds ratios of eHLQ scores on HADS anxiety scores

Table 5 provides results for the regression analysis of cancer health literacy on anxiety scoring. Results show there was no significant association between cancer health literacy and anxiety scores (OR= 0.89, p= 0.80). Age was significantly associated to anxiety level (OR= 0.23, p<0.001), suggesting that those who are 65 years and older are less likely to have anxiety scores outside the normal range, according to the HADS anxiety subscale. Educational attainment and race showed no significant associations to anxiety scores among the respondents in this study.

	df	Unadjusted Odds Ratio (95% CI)	p	Adjusted Odds Ratio (95% CI)	p
CHLT-6	1	0.75 (0.38, 1.50)	0.42	0.89 (0.36, 2.17)	0.80
<b>Covariates</b>					
Age	1	-	-	0.23 (0.11, 0.51)	<0.001*
Education (Less than HS)	2	-	-	1.0	0.70
Education (HS diploma)	1	-	-	0.91 (0.26, 2.09)	0.86
Education (More than HS)	1	-	-	0.64 (0.19, 1.85)	0.48
Race (White)	2	-	-	1.0	0.37
Race (Black)	1	-	-	1.61 (0.50, 4.99)	0.40
Race (Other)	1	-	-	0.89 (0.16, 4.39)	0.80

p<0.05\*

Table 5. Odds ratios of CHLT-6 scores on HADS anxiety scores

Binary regression results between eHLQ domains and information processing style are included in Table 6. Of the seven domains, domain 3 (ability to engage with digital services) showed a significant inverse association to monitoring level (OR= 0.21, p= 0.02). Domain 2 (OR= 3.43, p=0.15) and domain 7 (OR= 2.72, p= 0.14) scores reflect strong positive associations between eHealth literacy factors and high monitoring; however, these findings were not statistically significant. While most of the covariates showed non-significant association to monitoring style, those who identified as Black

(OR= 3.57, p= 0.04) were much more likely to be classified as high monitors, compared to Non-Hispanic White respondents.

	<b>df</b>	<b>Unadjusted Odds Ratio (95% CI)</b>	<b><i>p</i></b>	<b>Adjusted Odds Ratio (95% CI)</b>	<b><i>p</i></b>
eHLQ 1	1	2.09 (0.53, 8.20)	0.29	1.19 (0.24, 5.90)	0.83
eHLQ 2	1	2.03 (0.50, 8.25)	0.32	3.43 (0.64, 18.26)	0.15
eHLQ 3	1	0.22 (0.07, 0.64)	0.01*	0.21 (0.06, 0.74)	0.02*
eHLQ 4	1	1.03 (0.33, 3.22)	0.96	1.73 (0.46, 6.48)	0.42
eHLQ 5	1	0.85 (0.20, 3.64)	0.82	0.84 (0.18, 3.94)	0.82
eHLQ 6	1	0.56 (0.13, 2.35)	0.43	0.85 (0.17, 4.17)	0.84
eHLQ 7	1	3.62 (1.09, 12.05)	0.04*	2.72 (0.73, 10.21)	0.14
<b>Covariates</b>					
Age	1	-	-	1.70 (0.74, 3.91)	0.22
Education (Less than HS)	2	-	-	1.0	0.47
Education (HS diploma)	1	-	-	0.66 (0.22, 1.99)	0.46
Education (More than HS)	1	-	-	0.47 (0.14, 1.59)	0.22
Race (White)	2	-	-	1.0	0.06
Race (Black)	1	-	-	3.57 (1.07, 11.91)	0.04*
Race (Other)	1	-	-	1.22 (0.22, 6.71)	0.82

p<0.05\*; eHLQ 1: Ability to process information; eHLQ 2: Engagement in own health; eHLQ 3: Ability to actively engage with digital services; eHLQ 4: Feel safe and in control; eHLQ 5: Motivated to engage with digital services; eHLQ 6: Access to digital services that work; eHLQ 7: Digital services that suit individual needs.

Table 6. Odds ratios of eHLQ scores on Monitoring information processing

Lastly, Table 7 includes results of the binary regression analysis between cancer health literacy and information processing style. There was a statistically significant association between cancer health literacy and information processing (OR= 0.27, p=0.004), where individuals who scored in the lower cancer literacy category having greater odds to be classified as low monitors. While age (OR= 1.38, p= 0.40) and being of a racial minority (Black: OR= 2.09, p= 0.21; Other: OR= 1.38, p= 0.71) showed some potential associations, these findings were not statistically significant.

	<b>df</b>	<b>Unadjusted Odds Ratio (95% CI)</b>	<b><i>p</i></b>	<b>Adjusted Odds Ratio (95% CI)</b>	<b><i>p</i></b>
CHLT-6	1	0.27 (0.12, 0.58)	<0.001*	0.27 (0.11, 0.66)	0.004*
<b>Covariates</b>					
Age	1	-	-	1.38(0.65, 2.97)	0.40
Education (Less than HS)	2	-	-	1.0	0.94
Education (HS diploma)	1	-	-	0.94 (0.32, 2.79)	0.91
Education (More than HS)	1	-	-	1.10 (0.31, 3.97)	0.88
Race (White)	2	-	-	1.0	0.42
Race (Black)	1	-	-	2.09 (0.66, 6.58)	0.21
Race (Other)	1	-	-	1.38 (0.26, 7.45)	0.71

p<0.05\*

Table 7. Odds ratios of CHLT-6 scores on Monitoring information processing

## Discussion

Our current study provides novel insights into the associations between critical types of literacy (eHealth and cancer health) with anxiety, a common psychological comorbidity in cancer patients, and information processing, a behavior that can predict how patients seek, rely upon, and react to health information. Overall, we found that in relation to eHealth literacy, a patient’s “ability to actively engage with digital services” is associated to monitoring level, with those who perceive themselves as less able to interact

with health technology having decreased odds to be classified as “high monitors.” Cancer health literacy was also significantly associated with information processing, where individuals of inadequate cancer health literacy had lesser odds of being high monitors. Age was the only significant demographic variable when assessing relationships to patient anxiety, with patients 65 and older displaying lower odds of scoring within the borderline/case range in the HADS-A subscale. Race was a significant covariate in the assessment of eHealth literacy and information processing style, with Black patients having increased odds of being classified as “high monitors” compared to White patients.

While neither eHLQ nor cancer health literacy were significantly associated with anxiety in our analysis, increasing age was found to be a significant predictor for lower anxiety. This finding matches previous work on anxiety rates among cancer patients. Although some have shown that older cancer patients might report increased anxiety, other studies show this relationship might be associated with other factors, such as pain, and can decrease when such conditions are managed (Roth, 2003). In a comparative study of prostate cancer patients, researchers found that increasing age was associated with less anxiety and distress, and greater emotional quality of life (Nelson, 2009). Similarly, a study on elderly (65 and older) Medicare beneficiaries found that compared to individuals without cancer, colorectal cancer patients reported an average of 0.3% lower anxiety (Zhang, 2010).

It should be noted that participants in our study were cancer patients from the Philadelphia Metro area, primarily Black, of low financial resources and Medicare and/or Medicaid as health insurance. In our analysis Non-Whites had significantly greater odds of exhibiting moderate to severe anxiety and being classified as “high monitors.” Our

findings suggest that Black cancer patients report greater anxiety and aligns with prior findings in cancer patients from minority racial/ethnic groups, but also supports the relationship that high monitors also have higher anxiety. Assessment of psychological distress in cancer patients in California and Louisiana found that Non-White patients were more likely to experience distress and report poorer mental health (Alcala, 2014; Perry, 2020). Studies on Black breast cancer survivors have also shown racial minorities, including Black and Asian patients, have a higher likelihood to present symptoms of clinical anxiety (Patel-Kerai, 2017; Lake, 2022).

Regarding information-seeking behaviors among Black patients, some studies suggest Non-Hispanic White cancer patients are more likely than Blacks to actively look for health information (Thompson, 2008). Importantly, our sample of patients were less likely to have adequate cancer health literacy in comparison to other studies (Kanu, 2022; Hyatt, 2021). Nevertheless, more recent literature points to increasing reliance on the Internet by Black patients as a source of health information (Rooks, 2012; Sherman, 2021; Silwal, 2022). Such growing trends underscore the value of better understanding the relationships between eHealth literacy and information processing, and how patients might be better assisted to find useful, reliable, and relevant cancer-related information online.

Trend analysis from the Health Information National Trends Survey (HINTS) shows that Internet health information-seeking has increased among cancer survivors (Jiang, 2019). Yet, our findings suggest an inverse association between domain 3 of the eHLQ (ability to engage in digital services) and high monitoring. These results appear to contradict contemporary work suggesting that lower health literacy is associated with

greater health information overload, which would hinder information-seeking, or monitoring, practices (Khaleel, 2020). One possible factor influencing this outcome is how items within domain 3 of the eHLQ might be interpreted, depending on the level of eHealth literacy and resources that respondents have been previously exposed to, and their personal interpretation of health technology. For example, an item within this domain is worded as: “I quickly learn how to find my way around new technology;” a respondent’s answer to such an item may depend on what type of technology they recall at the time of the survey or how they interpret the word “technology.” which would depend on their past experiences, resources and range of access to different digital tools. As patients become exposed to sources of both reliable and unreliable information, part of the mission of increasing eHealth literacy is to provide education that allows patients to discern and select useful and trustworthy online health information tools.

This study has some limitations. Our use of a convenience sample of patients within the city of Philadelphia provides results that are not representative of all cancer patients in the US. However, respondents in the sample provided valuable information on the impact of literacy in subgroups that are often underrepresented across research studies, such as Black/African Americans and low-income populations. Additionally, the sample size in this study is likely to dampen some potential effects, as seen by the larger confidence intervals for some variables. Furthermore, the combination of some demographic categories due to small cell numbers might impact the interpretability of some of these results. In the future, larger studies assessing these variables might provide more significant and granular insight into these relationships.

## **Conclusion**

Exploring the associations of eHealth literacy and cancer health literacy with patient anxiety and information processing style, our study determined that race, age, a prior cancer diagnosis and how patients engage with electronic devices can have meaningful impact on these factors. These findings are useful in the tailoring of interventions to account for preferences on information-seeking and provide mental health support to patients most in need. While some findings were unexpected, such as lower monitoring among patients who engage more with digital services, they also point out to a need for flexibility for patients who might need support to better adopt eHealth tools in ways that meet their literacy levels as well as their needs and expectations.

## **Chapter 4: Manuscript 3**

### **Moderation Effects of eHealth Literacy and Cancer Health Literacy Between Information Processing Style and Cancer Anxiety**

#### **Introduction**

Patients who suffer from chronic conditions are often exposed to complex medical information that might prove overwhelming. Nevertheless, acquiring, understanding, and applying health information is a critical component of patient engagement and shared decision-making, which can result in patients having more positive experiences throughout their care (Oh, 2012; Tan, 2017). Cancer patients may be more likely to undergo complicated medical treatment, have consistent interactions with medical staff, and utilize online health resources to make treatment decisions (Berger, 2018). As health information sources become more readily available online, a patient's ability to understand and assess the quality of these resources, as well as to interpret care information and results becomes imperative (Manganello, 2017). In the case of patients with cancer, electronic health (eHealth) literacy, skills that provide "the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem" are particularly important due to the time-sensitive nature of making treatment decisions (Norman, 2006).

While validated health literacy measures have been widely available for decades, the literature, theoretical models, assessments, and interventions on eHealth literacy have largely developed over the past 15 years. eHealth literacy has been addressed within the context of intentions to use health technology, usability testing studies, and intervention studies towards preventative care and health management (Apter, 2019; Nahm, 2019;

Stein, 2018). Nevertheless, eHealth literacy testing, through inclusion of validated measures such as the 8-item eHealth Literacy Scale (eHEALS), is seldom included along with other patient-reported assessments in research studies, particularly those examining its association to health outcomes (Norman, 2006). Similarly, disease specific literacy is also important. In the case of conditions such as cancer, which require the acquisition of specific, complex medical information, adequate general health literacy might not be representative of a patient's cancer-specific knowledge. This disparity was shown in a 2021 cross-sectional study, screening cancer patients using a general health literacy tool and a cancer-specific health literacy measure. This study found that while 16.8% of participants displayed adequate health literacy on the general health literacy scale, they tested as inadequate on the cancer health literacy scale (Hyatt, 2021).

Previous work on the moderating effect of health and eHealth literacy has shown their role in the association between information-seeking, preventive behavior, and cognitive outcomes to cancer (Dominick 2015; Oh, 2019; Chen, 2018, Li 2020; Chung 2019). For example, an intervention study among first-generation Latinas to enhance physical activity found health literacy moderated the association between treatment and intervention effects (Dominick, 2015). Health literacy has also been shown to positively moderate perceptions of a health message's importance and intentions to verify and share such messages (Oh, 2019; Chen, 2018). In a cross-sectional assessment on the moderating effects of eHealth literacy and disease knowledge, investigators found eHealth literacy had a significant moderating effect on the relationship between social media use frequency and preventive COVID-19 behaviors (Li, 2020). A study on cancer information and its impact on cancer fatalism found higher education and eHealth literacy

moderated this relationship, with those of lower education and eHealth literacy experiencing increased levels of cancer fatalism with greater exposure to cancer information on health websites (Chung, 2019). Recent work on the impact of using quantifiers on cancer messaging on intentions to screen for colorectal cancer in the UK found cancer health literacy was marginally associated with positive intentions to screen after exposure to the message (Stoffel, 2019).

While the association between information-seeking and anxiety in cancer has been previously analyzed, results vary across studies, which points to the complexity of cognitive-affective behaviors under challenging health threats. In a study on the psychological ramifications of ovarian cancer screening, researchers found women with a higher information-seeking processing style had greater levels of distress (Wardle, 1993). A study on information processing and its effect using data from the Health Information National Trends Survey (HINTS) determined that individuals who paid more attention to health information were statistically more likely to exhibit higher cancer-related worry (Beckjord, 2008). These findings align with a review by Roussi and Miller (2014), which concluded that monitors, defined as individuals who have "...temporally stable dispositional tendency to attend to, scan for, and amplify threatening health-related cues or information" (Miller, 2015), while often more knowledgeable and resourceful than low monitors, tend to exhibit more negative affective outcomes (Roussi, 2014; Miller, 2015). Nevertheless, a 2018 study on monitoring coping style and affective outcomes during the cancer diagnosis found that higher information processing (monitoring) was associated with reduced anxiety among this patient sample (Bronner, 2018). Although such results

suggest the possibility of opposite outcomes, all these studies present compelling evidence on the effect of information processing style on anxiety and distress.

What is not known, however, is if having high eHealth or cancer health literacy might moderate these effects. Thus, the aim of this study was to assess the moderating effects of eHealth literacy and cancer health literacy between information processing and anxiety. To address this, we focused our analysis on the following hypotheses:

**Hypothesis 1:** eHealth literacy will show moderating effects between information processing and patient anxiety.

**Hypothesis 2:** Cancer health literacy will show moderating effects between information processing and patient anxiety.

This study provides the first assessment of the potential moderating effects of eHealth and cancer health literacy in the association between information processing style (high v. low monitoring) and cancer-specific patient anxiety.

## **Methods**

### ***Participant recruitment and survey administration***

The oncology department at Temple University Hospital in Philadelphia, PA was the primary site for participant recruitment. TUH oncology provides care to mostly underrepresented, underserved patients in active cancer treatment; the majority are ethnic and racial minorities who have Medicare/Medicaid health insurance (Temple University Hospital, 2019). Inclusion criteria in this study required all participants (n=153) to be 18 years or older, have an active cancer diagnosis, and undergoing treatment or follow-up for such condition. Patients unable to read or understand English were excluded from participating. For the purposes of inclusion criteria, an active cancer diagnosis was

defined as "...not received potentially curative treatment, or when there is evidence that treatment has not been curative" (e.g., recurrent, or progressive disease) (Kearon, 2016). Our study was deemed exempt by the Temple University Institutional Review Board prior to participant recruitment (protocol number: 29400).

Data for this study was collected between June and September 2022. Study staff were responsible for all survey data collection and received training on approaching potential respondents, obtaining patient consent, and assisting with the survey administration process prior to the beginning of data collection. Before participant enrollment, research assistants would ask three questions to verify participants met the inclusion criteria, asked for verbal consent, and provided consenting patients with the necessary time to go over documentation on confidentiality, risks, benefits, and compensation. Copies of the consent form and information were available for participants to take with them, if desired. All surveys were provided as paper copies and completed by participants while waiting for their scheduled appointments, or while receiving treatment. Respondents were given the option to complete the survey with assistance to accommodate for visual/hearing impairment and literacy. On average, each survey packet took approximately 15 minutes to complete. Respondents who completed and returned the survey were compensated with a \$15 gift card to a local store.

### *Survey Measures*

**Demographic characteristics.** Questions to assess participants' demographic characteristics included: age, highest level of education completed, type of insurance patient had, race, Hispanic/Latinx ethnicity, annual household income, gender, marital

status, was this their first cancer diagnosis, type of cancer (primary site) of their diagnosis and current cancer stage.

**eHealth literacy.** eHealth literacy was assessed through the eHealth literacy questionnaire (eHLQ), developed by Kayser (2018). The eHLQ is a 35-item questionnaire, using a 4-point Likert response scale (strongly disagree, disagree, agree, strongly agree). The questionnaire includes seven domains composed by non-overlapping items: (1) ability to process information (5 items,  $\alpha= 0.84$ ), (2) engagement in own health (5 items,  $\alpha= 0.77$ ), (3) ability to engage with digital services (5 items,  $\alpha= 0.86$ ), (4) feeling safe and in control (5 items,  $\alpha= 0.86$ ), (5) motivation to engage with digital services (5 items,  $\alpha= 0.85$ ), (6) access to digital services that work (6 items,  $\alpha= 0.77$ ), and (7) digital services that suit individual needs (4 items,  $\alpha= 0.85$ ) (Kayser, 2018). eHLQ scoring results in seven independent mean scores, each ranging from 1 to 4. All items found within each domain are weighted equally to calculate the domain's mean score (Kayser, 2018). Increasing scores in each domain are indicative of higher eHealth literacy for that particular scale, each of which are reported separately (Kayser, 2018).

**Cancer Health Literacy.** Dumenci and colleagues' Cancer Health Literacy Test-6 (CHLT-6) was used to determine individuals with limited cancer health literacy. This 6-item test includes 4 multiple choice questions and 2 true or false questions, which examine patient knowledge on various aspects related to the cancer experience, such as reading lab results, stages of cancer diagnosis, medical terminology of treatment, and basic numeracy. A low burden test, the CHLT-6 can be administered in about 2 minutes. Measurement invariance analysis has shown high internal validity ( $\alpha= 0.88$ ) across gender and race/ethnicity. The CHLT-6 displays a high degree of precision, with large

differences in probability of accurate responses to the 6 items between those with limited and adequate cancer health literacy. Scores for the CHLT-6 range from 0 to 6, with a point awarded per correct answer. Validation of the CHLT-6 supported a dichotomous classification of results, with those scoring between 0 and 4 said to have limited cancer health literacy, while those scoring a 5 or 6 found to have adequate cancer health literacy (Dumenci, 2014).

**Information processing.** The monitoring processing style in this study was measured using the Miller Behavioral Style Scale Short Form (MBSS-SF). This instrument reflects cognitive and affective characteristics individuals might follow when facing threatening situations (Miller, 1987), including being “monitors”, or information seekers, or “blunters, information avoiders. The Monitoring subscale of the MBSS includes 16 items, with 4 yes/no questions included in each of 4 threat scenarios: a dentist appointment, a terrorist hostage scenario, threat of job loss, and a turbulent plane flight. Each of the four items per scenario focuses on monitoring (information-seeking) behaviors. Before a set of questions is introduced, a short prompt describing the event is provided, followed by 4 statements where respondents answer whether they would or would not perform the behaviors described. This measure is scored by providing 1 point per affirmative response and no points for a negative response. Median sample score is used as the cutoff point between “high monitoring” (at or above the median) and “low monitoring” (scores below the median) (Bartle-Haring, 2008).

**Patient anxiety.** The Hospital Anxiety and Depression Scale (HADS) is a 14-item questionnaire developed to examine depression and anxiety in an outpatient setting, which has been widely validated across diverse subgroups, including cancer patients

(Zigmond, 1983, Mitchell, 2010). Reliability for the HADS-A subscale ranges between  $\alpha = 0.67-0.90$ , with a mean of 0.82 (Skapinakis, 2014). Anxiety being the primary health outcome, our survey included the anxiety subscale alone; this 7-item anxiety subscale can be used independently from the depression subscale as each is scored independently (Annunziata, 2020; Muzzatti, 2022). HADS items are scored using a 4-point scale, between 0 and 3, with total scores ranging from 0 to 21, through addition of points from the 7 items in the subscale. In the current study, we include a 3-level score classifications, which was eventually collapsed into 2 categories: normal (scores 0 through 7), borderline (moderate)/abnormal (scores 8 through 21) (Mitchell, 2010; Annunziata, 2020; Bjelland, 2002.)

### ***Statistical Analysis***

Simple moderation analysis employed was performed using the Hayes PROCESS add-on macro (Hayes, 2018). For hypothesis one, the moderation analysis examined the effects of each of the seven eHLQ domains on information processing and patient anxiety through seven models with interaction terms. In hypothesis two, a single moderation model was used to determine if CHLT-6 score, as a measure of cancer health literacy, showed moderating effects between information processing and anxiety level. This moderation analysis used 5000 bootstrap samples, which generate a confidence interval, used as the primary value to interpret moderation results. All moderation models were two-tailed, performed at a 95% confidence level, and were interpreted based on the inclusion of a value of zero within the confidence interval. Binary regression was also assessed to determine significant associations between information processing and patient anxiety. SPSS version 29 was used for all statistical analysis (IBM Corp, 2022).

Figure 1 visually depicts our hypotheses on the moderating effects of eHealth literacy and cancer health literacy between information processing style and cancer anxiety. Work by Tennant (2015) and Lee (2021) have previously suggested that health information seeking and sharing is associated with eHealth literacy and educational attainment. It has also been correlated with increased patient anxiety (Miller, 1987). While cancer literacy-specific moderating effects have not been previously assessed in this context, research on the moderating effects of general health literacy on quality of life outcomes in cancer patients and survivors make this factor a target of interest for this particular population (Samoil, 2021).

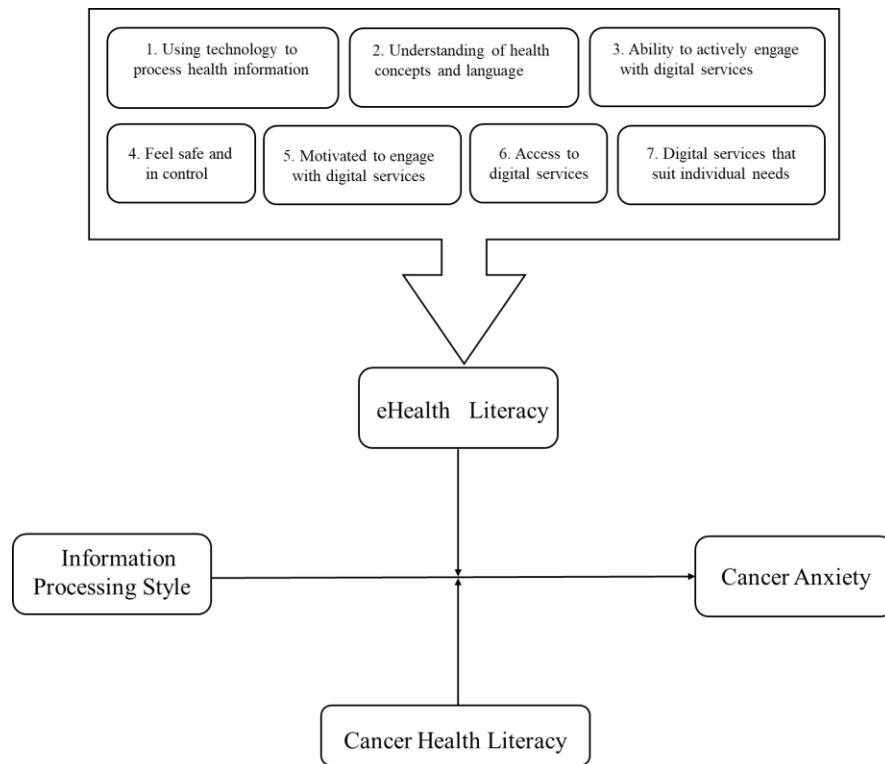


Figure 1. Moderating effect of eHealth literacy and cancer health literacy on the relationship between information processing and cancer anxiety

## **Results**

Table 1 includes demographic characteristics for the 153 survey respondents. The average age of respondents was 62.3 years (SD 11.0): 45.7% of participants were 65 years or older. Study participants were more likely to be female (63.4%), Black (74.1%), and have completed HS/GED as their highest level of education (45.4%). While less than three-fourths of participants reported their household income, 73.2% earned less than \$25,000 a year. Medicare and Medicaid were the primary sources of health insurance among respondents (68.4%). Further, 74.2% of participants reported this was their first cancer diagnosis; almost a third of the sample (32.7%) were unsure or did not know their current cancer stage at the time of survey.

<b>Overall</b>	<b>n= 153 (100%)</b>
<b>Characteristics</b>	
<b>Age at survey</b>	<b>n= 151</b>
18-44	11(7.3)
45-54	16 (10.6)
55-64	55 (36.4)
65-74	54 (35.8)
75+	15 (9.9)
<b>Gender</b>	<b>n= 153</b>
Male	54 (35.3)
Female	97 (63.4)
Other	1 (0.7)
<b>Race</b>	<b>n=143</b>
White	21 (14.7)
Black	106 (74.1)
Other	16 (11.2)
<b>Hispanic</b>	<b>n=150</b>
Yes	25 (16.7)
No	125 (83.3)
<b>Education</b>	<b>n= 152</b>
Less than high school	31 (20.4)
High school diploma/GED	69 (45.4)
Some college/vocational school	29 (19.1)
College graduate or higher	23 (15.1)
<b>Income</b>	<b>n=112</b>
Less than \$10,000-\$25,000	82 (73.2)
\$25,001-\$50,000	17 (15.2)
\$50,001-\$75,000	6 (5.4)
\$75,001 or greater	7 (6.3)
<b>Insurance</b>	<b>n= 136</b>
Private	31 (22.8)
Medicare/Medicaid	93 (68.4)
Unsure/Other	12 (8.8)
<b>Marital status</b>	<b>n= 151</b>
Married	33 (21.9)
Single	81 (53.6)
Divorced	24 (15.9)
Widowed	13 (8.6)
<b>First cancer diagnosis</b>	<b>n= 151</b>
Yes	112 (74.2)
No	39 (25.8)

Table 1. Demographic characteristics of patient respondents

<b>Cancer stage</b>	<b>n= 153</b>
1	33 (21.6)
2	18 (11.8)
3	18 (11.8)
4	34 (22.2)
Unsure/Missing	50 (32.7)

Table 1 continued. Demographic characteristics of patient respondents

Table 2 includes means and standard deviation scores of the seven domains of the eHLQ. Due to incomplete survey responses, one survey was excluded from this analysis. Based on scoring recommendations, overall mean values including all domains is not calculated for the eHLQ. For our sample, the lowest mean score was for domain 3 at 2.86 (ability to actively engage with digital services) and the highest mean score was for domain two at 3.10 (engagement in your own health).

<b>Domain</b>	<b>Mean (SD)</b>
1. Ability to process information	2.87 (0.55)
2. Engagement in own health	3.10 (0.42)
3. Ability to actively engage with digital services	2.86 (0.57)
4. Feel safe and in control	2.99 (0.51)
5. Motivated to engage with digital services	2.97 (0.50)
6. Access to digital services that work	3.02 (0.43)
7. Digital services that suit individual needs	2.87(0.53)

Table 2. eHLQ domain sample mean scores

Table 3 presents participant score percentages for the CHLT-6, HADS-A and MBSS-Monitoring. Response rates to the CHLT-6 was 96.7%, with most participants being classified as having limited cancer literacy (59.5%). Response rate to the HADS-A was 88.2%, and most participants scored within the “normal” range (63.7%). Response rate to the MBSS-M was 92.8%. Over half of the respondents were classified as “low monitors” (56.2%).

<b>Measures</b>	<b>N (%)</b>
<b>CHLT-6</b>	
Limited	91 (59.5)
Adequate	57 (37.3)
<b>HADS-A</b>	
Normal	86 (63.7)
Borderline	17 (12.6)
Abnormal	32 (23.7)
<b>MBSS-M</b>	
Low monitoring	86 (56.2)
High monitoring	56 (36.6)

Table 3. Cancer health literacy, patient anxiety, and information processing classifications

Table 4 contains regression results on the relationship between information processing and patient anxiety level. These results show monitoring is not statistically significantly associated to anxiety for respondents in this sample. Table 5 includes results on the analysis to determine the moderating effect of the domains of the eHLQ in the relationship between information processing and patient anxiety. As shown, no statistically significant interaction effects were observed for any of the domains of the eHLQ, with all confidence intervals including zero and  $R^2$  scores of zero across all models.

	<b>df</b>	<b>Odds ratio</b>	<b>95% CI</b>	<b>p</b>
Constant	1	0.67	-	0.09
MBSS-M	1	0.94	0.47, 1.88	0.87

Table 4. Correlation between information processing and patient anxiety

	$\beta$	SE	$t$	$p$	LLCI	ULCI	$R^2$
<b><i>eHLQ Domain 1</i></b>							
Constant	1.65	0.09	17.83	0.00	1.47	1.83	0.00
MBSS-M	-0.04	0.15	-0.24	0.81	-0.33	0.26	
eHLQ 1	-0.01	0.17	-0.03	0.97	-0.34	0.34	
Interaction	0.05	0.27	0.19	0.85	-0.48	0.59	
<b><i>eHLQ Domain 2</i></b>							
Constant	1.64	0.09	17.78	0.00	1.46	1.83	0.01
MBSS-M	-0.02	0.15	-0.13	0.90	-0.31	0.28	
eHLQ Domain 2	-0.16	0.21	-0.78	0.43	-0.57	0.24	
Interaction	0.04	0.37	0.11	0.91	-0.68	0.76	
<b><i>eHLQ Domain 3</i></b>							
Constant	1.65	0.09	17.89	0.00	1.47	1.83	0.00
MBSS-M	-0.03	0.15	-0.19	0.85	-0.32	0.27	
eHLQ Domain 3	-0.02	0.16	-0.14	0.89	-0.33	-0.28	
Interaction	0.16	0.26	0.62	0.53	-0.35	0.68	
<b><i>eHLQ Domain 4</i></b>							
Constant	1.65	0.09	17.85	0.00	1.47	1.83	0.00
MBSS-M	-0.03	0.25	-0.18	0.86	-0.32	0.27	
eHLQ Domain 4	-0.03	0.17	-0.15	0.88	-0.37	0.32	
Interaction	-0.09	0.29	-0.30	0.76	-0.66	0.49	
<b><i>eHLQ Domain 5</i></b>							
Constant	1.66	0.09	17.95	0.00	1.47	1.84	0.01
MBSS-M	-0.04	0.15	-0.28	0.78	-0.33	0.25	
eHLQ Domain 5	0.16	0.18	0.92	0.36	-0.19	0.52	
Interaction	-0.14	0.31	-0.44	0.66	-0.75	0.47	
<b><i>eHLQ Domain 6</i></b>							
Constant	1.65	0.09	17.92	0.00	1.46	1.83	0.01
MBSS-M (Model 6)	-0.04	0.15	-0.27	0.78	-0.33	0.25	
eHLQ Domain 6	-0.18	0.20	-0.92	0.36	-0.58	0.21	
Interaction	0.48	0.37	1.32	0.66	-0.24	1.21	
<b><i>eHLQ Domain 7</i></b>							
Constant	1.65	0.09	17.77	0.00	1.47	1.84	0.00
MBSS-M (Model 7)	-0.05	0.15	-0.30	0.76	-0.34	0.25	
eHLQ Domain 7	0.01	0.17	0.04	0.97	-0.33	0.34	
Interaction	0.11	0.28	0.38	0.70	-0.4	0.67	

LLCI = Lower Level Confidence Interval; ULCI= Upper Level Confidence Interval

Table 5. Moderation effects of eHealth literacy (eHLQ) domains on the relationship between information processing style and anxiety

Results on the moderation effects of cancer health literacy (CHLT-6) on information processing and patient anxiety are presented in Table 5. Similarly to the eHLQ findings, no measurable interaction effects were determined in this model, with zero being found within the 95% confidence intervals. Based on results summarized in tables 4 and 5, neither hypothesis was supported by our findings.

	$\beta$	SE	<i>t</i>	<i>p</i>	LLCI	ULCI	<i>R</i> <sup>2</sup>
Constant	1.65	0.13	12.30	0.00	1.38	1.92	0.00
MBSS-M	-0.02	0.19	-0.12	0.91	-0.39	0.35	
CHLT-6	-0.08	0.19	-0.42	0.68	-0.45	0.29	
Interaction (CHLT-6*MBSS)	0.20	0.33	0.60	0.55	-0.46	0.86	

LLCI = Lower Level Confidence Interval; ULCI= Upper Level Confidence Interval

Table 6. Moderation effects of cancer health literacy (CHLT-6) on the relationship between information processing style and anxiety

## Discussion

Existing work on the associations between information processing and health and eHealth literacy, as well as on mental health outcomes among patients with cancer and other chronic illnesses was the primary driver behind the current study (Bronner, 2018). Our study aimed to assess the moderating effects of eHealth literacy and cancer health literacy, focusing on two primary hypotheses. In hypothesis 1, we predicted that some or all the domains of the eHLQ, which were independently tested, would show significant moderating effects between information processing style (high v. low monitoring) and patient anxiety (normal v. borderline/abnormal clinical anxiety scores). For hypothesis 2, we predicted that cancer health literacy, measured through the CHLT-6, would have significant moderating effects between information processing and patient anxiety. While our findings suggest otherwise, we will discuss possible insights of the current results,

limitations in our study that could have contributed to these findings, and future steps that could be useful in comparing these results.

Our analysis in this study did not support the hypothesis that the domains of the eHLQ would significantly moderate the relationship between information processing and anxiety. While sign differences across coefficients suggested some domains could have a positive effect (1, 2, 3, 6, and 7), while others might have a negative effect (4 and 5), none of these findings were statistically significant. Assessments on the moderating effect of cancer health literacy – hypothesis 2 - between information processing and patient anxiety were also non-significant. Although previous evidence supports some moderating effects for health and eHealth literacy on the perceived importance of health messaging and adherence to health prevention guidellines (Oh, 2019; Li, 2020), an assessment of eHealth literacy as a positive moderator between the implementation of a decision aid on mammography and health knowledge found no significant moderating effects (Reder, 2019). While previous studies have found significant correlation between information-seeking, a concept with some overlap with information processing, and patient anxiety, our analysis showed no statistically significant association between these variables. The lack of significant relationship between these factors is thus a principal reason for the absence of significant moderating effects found in this study.

Research on information processing on affective outcomes supports a positive association between active information-seeking (high monitoring) and a greater likelihood to experience distress, anxiety, and dissatisfaction with healthcare experiences (Wardle, 1993; Beckjord, 2008; Roussi, 2014). While we proposed such effects could be associated with literacy, other factors, such as information overload, could account for

some of these findings. A study by Chae and colleagues (2016) determined that cancer overload, defined as “...aversive disposition wherein a person is confused and overwhelmed by cancer information” was significantly associated with trait anxiety, but not with use of health information (Chae, 2016). Further, a study using 2003 Health Information National Trends Survey (HINTS) data determined that information-seeking was significantly associated with cancer information overload; however, this study found no relationship between Internet use and cancer information overload (Kim, 2007). One factor that further complicates these relationships is the transformational impact of the Internet throughout our lives over the past couple of decades. It has become ubiquitous for most, and especially for people with cancer; results from a 2019 study reported more than 90% of cancer patients used the Internet as a source of health information (Braun, 2019). Thus, the growing importance of Internet-driven tools in healthcare can add further complexity to the ways we interpret and compare these findings.

Limitations in our study might partially account for the lack of moderating effects we found in our analysis. The inclusion of a convenience sample with a limited number of respondents could impact the power of our findings. In future assessments, a larger and more representative sample of participants would be useful in determining if the current findings truly characterize a lack of moderating effects of eHealth literacy and cancer health literacy between information processing and patient anxiety. In this study, our assessment of cancer diagnosis was limited to self-reported information by patient respondents and did not include date from the primary diagnosis. Such limitation in information has the potential to bias our assessment on anxiety; research has shown that levels of anxiety can change across the cancer spectrum and throughout the cancer

experience, which we are unable to account for in the current analysis (Niedzwiedz, 2019). Additionally, possible correlates between information processing with eHealth literacy and/or cancer health literacy could have accounted for some of the missing moderating effects in the current analysis. To our knowledge, this study provides the first moderation analysis using the eHLQ as a measure of eHealth literacy and the CHLT-6 to assess cancer health literacy. Thus, more widespread utilization of these tools and additional instances of moderation analysis will be necessary in order to provide further evidence on the moderating effects of these types of literacies.

### **Conclusion**

The findings in our current study do not suggest that eHealth literacy or cancer health literacy significantly moderate the relationship between information processing style and patient anxiety. Results may be affected by the limited sample size or the inability of the tools to adequately assess the effects. Future studies assessing the moderating effects of eHealth and cancer health literacy should take into consideration the need for larger, representative samples that might more adequately reflect these associations.

## Chapter 5: Discussion of Main Findings

### Introduction

The manuscripts from this dissertation provide new information regarding the factor structure of the eHealth Literacy Questionnaire (eHLQ), and its associations with cancer health literacy, information processing style, and patient anxiety. The purpose of this study was to provide the first implementation of the eHLQ in a US patient population and to examine how this skill relates to the study variables, utilizing four theoretical frameworks: 1. The eHealth Literacy Framework, the Cognitive-Social Health Information-Processing Model, the Health Literate Care Model, and the Cancer Related Anxiety Model. This is the first study to utilize these frameworks together to elucidate how eHealth literacy can be measured and used in social and behavioral public health research.

Importantly, while digital health technology has been deployed to enhance healthcare experiences and patient satisfaction, research shows the availability of these resources alone is insufficient to improve health outcomes (Jiang, 2018; Dunn, 2019). In all its applications, technology is driven by change towards continuous improvement and relevance. Due to this implicit characteristic, adequate eHealth literacy becomes pivotal to the patient-user, not only to adopt digital health technology, but to be prepared to adapt for when such tools inevitably change. Despite the increasing importance of digital health and the skills that are needed to navigate it to inform healthcare decision making, an adequate measurement of it is lacking. The current eHealth Literacy Questionnaire (eHLQ) currently requires measurement of seven domains, each of which is independently scored, making practical and clinical use difficult.

This study shows that the domains of the eHLQ do fit a unidimensional latent factor model of eHealth literacy, providing the first step towards making this comprehensive, robust instrument an alternative to previously validated measures. We also provide evidence that domains of the eHLQ, as components of eHealth literacy, as well as cancer health literacy (measure with the validated CHLT-6) are significantly associated with information processing style. These findings suggest that individuals who display adequate cancer literacy and feel more confident to employ digital health services are at decreased odds of exhibiting high monitoring behavior, previously associated with more negative affective outcomes, decisional regret, and greater dissatisfaction with health experiences and providers (Roussi, 2014). This suggests that increasing a patient's eHealth and cancer literacy skills could have significant effects on negative affective outcomes during their cancer journey.

**The main findings of this research were:**

1. **The seven domains of the eHealth Literacy Questionnaire (eHLQ) showed fitness under a unidimensional model of eHealth Literacy.** Such findings suggest the possibility of developing a cohesive definition for this concept, and the opportunity to calculate a global score for eHLQ surveys, which would simplify interpretability and application of this instrument in clinical research settings.
2. **Information processing style (monitoring) is associated with subdomains of the eHLQ and cancer health literacy level.** These results suggest that greater ability to engage with digital services - domain 3 of the eHLQ - is associated with lower odds of displaying “high monitoring” processing style or being more likely to actively seek health information. An inverse association between cancer health

literacy and information processing was also significant. In this case, individuals with adequate cancer literacy have less odds to be classified as “high monitors” compared to those with inadequate literacy.

3. **Age and race are significant covariates in the association between eHealth literacy, information processing and anxiety.** Regression analysis shows individuals 65 years and older have reduced odds of displaying signs of clinical anxiety, compared to their younger counterparts. Furthermore, Black cancer patients have significantly greater odds of displaying high monitoring behaviors, and thus, display more awareness when encountering a health threat.
4. **eHealth literacy and cancer health literacy do not moderate the relationship between information processing and anxiety in our patient sample.** Although previous research bolsters the moderating effects of health literacy between information processing and patient anxiety, our current analysis does not support these factors as moderators.

#### **“The cart before the horse”: Why more eHealth literacy assessment is needed**

A comprehensive review of the literature on eHealth literacy in cancer patients and caregivers, between 2000 and 2021, found only 2 studies assessing levels of eHealth literacy in these populations in the United States (Verma, 2022). A cross-sectional study of partners of men with localized prostate cancer diagnosis by Symes and colleagues (2015) found overall low eHealth literacy scores in this population (Symes, 2015). In a 2020 cross-sectional study by Hoogland assessing age differences in eHealth literacy and the use of health information technology in cancer patients, those patients 65 years of age and older were significantly more likely to exhibit low eHealth literacy (Hoogland,

2020). Nevertheless, research as far back as 2005 has been examining and profiling the user of now widely used health technology, such as patient portals and electronic health records (Lin 2005; Weingart, 2006). This lag in assessing eHealth literacy as health technology becomes more commonplace is a critical issue in the field.

Characterizing patients who use health technology and those who do not should intrinsically consider basic skills proposed by Norman in the development of the eHEALS, such as computer literacy, information literacy, and health literacy (Norman, 2006). It should also take into account the motivation a patient has for health information-seeking, how much they value additional information, and/or how comfortable the patient feels making their own decisions compared to delegating these to a trusted health professional. While no practical instrument can fully describe the eHealth literacy needs of all patients, the intersectional work between information technology experts, clinicians, patients, and scientists that led to the development of the eHealth Literacy Framework resulted in a questionnaire that better represents the intricacies of the existing digital technology world (Kushniruk, 2012).

With technological breakthroughs being continually integrated into health, such as artificial intelligence-assisted applications for patient support, which rely less and less on patient-provider engagement, gauging the patient's understanding and motivation to engage with health technology becomes even more pressing (Kang, 2023). As we continue to untangle the impact of health disinformation and distrust in the healthcare system at the height of the COVID-19 pandemic, early studies have pointed to the value of basic health and digital literacy towards being able to discern across information resources and adhere to recommended guidelines (Guo, 2021; Sykes, 2022). It is

important that we understand that many of the obstacles in health communication experienced during this crisis might continue to impact patients throughout the rest of their healthcare experiences. To address such challenges, more widespread understanding of the state of eHealth literacy in a wider scope of patients is necessary. Furthermore, as literacy interventions are developed or implemented, using eHealth literacy as an outcome measure, gauging improvements over time, and assessing how this skill relates to uptake and long-term implementation will be essential in making practical tools that can stand the test of time.

**If you build it, and they still don't come: balancing knowledge and preferences, while safeguarding mental health**

Choosing patient anxiety as the health outcome of this study was informed by the consistent evidence of an increased likelihood of anxiety associated with a cancer diagnosis, its association with information processing, as well as the dearth of eHealth literacy measures used in association with a clinically measurable outcome (Curran, 2017; Naser, 2021). In our analysis, particularly our findings in Manuscript 2, we address how some participant demographic characteristics are associated with increased odds for anxiety, or are associated with high monitoring style, which has been correlated to negative affect and increased distress (Roussi, 2014). Our findings suggest that increased age might be significantly associated with decreased odds for clinical anxiety, while Black race, although not statistically significant in our current analysis, could increase the odds for anxiety in this patient group. Black patients were also significantly more likely to report high monitoring behavior to threats, which could increase their risk for poor mental health outcomes.

These patient characteristics are of significance as older adults and racial minorities have been identified as lower users of eHealth tools and have poor eHealth literacy (Choi, 2013; Lee, 2016). Older adults are also more likely to suffer from cognitive deficiencies or have difficulty hearing and/or seeing, which provide added obstacles towards the utilization of Internet-driven resources (Wilson, 2021). Also, to the oldest patients, who had a lifetime of primarily interpersonal patient-provider experiences, alternatives might not be welcomed, regardless of features that address literacy and communication tailoring that addresses their information-seeking needs and desires.

Black cancer patients, who were the primary demographic group in our sample, are likely to experience low eHealth literacy and socioeconomic disparities that limit their resources, as well as their well-being (Anderson, 2019; Walker, 2020; Abdel-Rahman, 2021). This creates challenges from assessment and implementation to education and tailoring of eHealth technology to a group's needs. Based on our current findings, Black cancer patients are more likely to respond to their health threat through rumination, seeking information, and staying alert to news regarding their diagnosis, while lacking the adequate eHealth and cancer health literacy necessary to use eHealth tools in ways that meet their informational needs. Thus, in developing and updating online health resources, researchers must take into consideration how to use health technology driven by individual needs. As personalized medicine takes the genomic underpinnings of a patient to improve health outcomes, so should health communication technology rely on personal choice, knowledge and behaviors that will lead to better use of eHealth tools and contribute to better outcomes.

## **Limitations**

Our study had some limitations. As mentioned, our use of a convenience sample methodology limits the interpretability of our findings to a specific patient population in the United States. Due to time and resource constraints for recruitment, our final sample size was significantly smaller than we had initially planned. This certainly had an impact, requiring adjustments in our analysis, including the collapsing of variable categories. Such modifications are likely to have dampened some of the results we observed, particularly for Manuscript 3, where no significant findings were detected.

While our survey focused on a small number of standard demographic and disease-related variables, some of these important factors had to be excluded due to the extent of missing answers. About one-third of participants provided no information regarding household income. While other socio-economic factors, such as highest educational attainment, are more relevant for our current analysis, this characteristic would provide some additional insight into the resources our sample population have to sustain access to the Internet and digital devices.

Additionally, about one-third of our sample was unable or unwilling to identify their cancer stage at diagnosis. This was a surprising finding, as we recruited patients who were mostly currently undergoing treatment. We determined most respondents had inadequate cancer health literacy, determining if differences in literacy are associated to cancer stage would provide useful information on the impact of disease severity on literacy. Lastly, our findings of such limited health and cancer literacy in our sample population suggest these limitations extend to basic literacy. If such was the case, obstacles in respondents' basic reading and comprehension could have impacted their

ability to adequately respond to the survey without more hands-on assistance and further instructions.

### **Lessons Learned**

One important lesson from the completion of this research project is the value of inclusivity of groups commonly underrepresented in clinical research. Although the use of a convenience sample restrained the diversity of participants in this study, the demographics of patients in our study provide a great contrast from previous samples who were administered the eHLQ. Beyond the large representation of racial/ethnic minorities, the patients in our sample were primarily impoverished, with low levels of formal education and limited access to health and financial resources. The validation studies for the eHLQ, completed in the Netherlands by Kayser (2018) and Australia by Cheng (2021), were composed of primarily white and educated healthy participants using universal healthcare systems (Kayser, 2018; Cheng 2021). Interacting with the patients in our sample made us aware of specific accommodations and support necessary for even baseline assessment of individuals with low basic literacy. Such experiences are helpful towards developing future research protocols in this area, as well as interventions involving patient training, who might require additional time, guidance, and instructions, beyond those that were anticipated.

As shown in our findings for Manuscript 1, our findings support a unidimensional latent factor model for the eHLQ, a more parsimonious, cohesive model compared to the 7-factor model recommended by Kayser and colleagues (2018). While the greater number of items in the eHLQ and inclusion of intention- and motivation-based questions provides an important element missing in former measures, the questionnaire is a high burden,

difficult to interpret instrument in its current form. One of the long-term objectives of the current research is to assess the feasibility of a short-form version of the eHLQ, which provides a single, global score that accounts for all domains. Developing a reliable, more easily administered, and interpretable form of the eHLQ would increase its usability in the clinical research setting and easier to use with populations who are starting at a lower level of health or eHealth literacy to begin with, such as the population that was sampled in this study. Importantly, this more accessible version of the eHLQ would also make it a more attractive outcome measure for use in future eHealth interventions, a much-needed feature largely absent from the digital health intervention literature.

## **Conclusion**

This dissertation had three primary objectives. First, to evaluate the goodness of fit of the eHLQ under a unidimensional model, like the eHEALS measure, but one that could more comprehensively assess the intricacy of eHealth literacy in a web 2.0 world (Norman, 2006). The evidence obtained here has the potential to be used in the development of a scoring methodology that allows for simpler ways to score, interpret, and compare eHLQ results. Second, assessment of eHealth literacy along cancer-specific literacy and how these critical skills relate to information processing behavior and patient anxiety provide evidence of how complex cognitive-behavioral processes interact under a health threat, and the ramifications for a patient's mental health. Lastly, we tested the potential moderating effects of eHealth and cancer health literacy on information processing and patient anxiety. While our analysis does not pinpoint significant moderation, analysis with a more extensive and diverse sample would be useful towards a clearer characterization of the relationships between these factors.

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## Appendix A. Survey Recruitment Packet



College of Public Health

Department of Social & Behavioral Sciences    *phone* 215-204-8726  
1301 Cecil B. Moore Avenue    *fax* 215-204-1854  
Ritter Annex – 9<sup>th</sup> Floor    *email* [publichealth@temple.edu](mailto:publichealth@temple.edu)  
Philadelphia, PA 19122    *web*: [www.temple.edu/publichealth](http://www.temple.edu/publichealth)

### **INFORMED CONSENT**

**Title of research:** Assessment of the eHealth Literacy Framework, Cancer Literacy and Cognitive-Social Health Information Processing in Cancer Patients

**Protocol Number:** 29400

**Investigators and Departments:** Sarah Bauerle Bass, PhD, MPH – Temple University, Department of Social and Behavioral Sciences; College of Public Health (Principal Investigator)

Maria Andrea Rincon, MPH, PhD Candidate - Temple University, Department of Social and Behavioral Sciences, College of Public Health (Student Investigator and Project Coordinator)

**Why am I being invited to take part in this research?:** We invite you to take part in a research study because you are a patient of Temple University Hospital, currently undergoing care and treatment for a cancer diagnosis. We aim to assess patient eHealth literacy, or knowledge and use of electronic and Internet-based sources for health information, cancer literacy and information-seeking behavior to understand its impact on patient mental health.

#### **What should I know about this research?**

- Someone will explain this research to you.
- Whether or not you take part is up to you.
- You can choose not to take part.
- You can agree to take part and later change your mind.
- Your decision will not be held against you.
- You can ask all the questions you want before you decide.

**Who can I talk to about this research?:**

<b>If you have questions about:</b>	<b>Please Contact:</b>
This study, complaints, or think the study has hurt you.	Dr. Sarah Bass, Temple University - 215-204-5110, sbass@temple.edu, 1301 Cecil B. Moore Ave., Philadelphia, PA 19122
If you have a concern or complaint, or questions about your rights as a research participant while you are in this study or after the study ends.	Institutional Review Board at Temple University - 215-707-3390 or email them at irb@temple.edu

**Why is this research being done?:** This study is being done to understand differences in eHealth (digital) literacy among patients. Increased use of the Internet as a source of health information shows eHealth literacy is an important skill towards gathering and using online health information to improve patient experiences with their care. We want to understand your perceptions and beliefs about your own literacy, ways you seek information, and your anxiety in order to better comprehend how these factors relate to each other, and how this might inform future improvements in patient education and health information resources.

**How long will I be in this research?:** You will be asked to answer survey questions that will take approximately 15 minutes to complete. The survey will be provided as a paper copy.

**What happens if I agree to be in this research?:** A survey administrator will review a paper consent form with you for your review (a copy of the form will be available for you to keep). After reviewing the consent form, you will be asked verbally if you consent to participate. If you agree, a survey administrator will provide you with a paper copy of the survey, where you will be asked to mark your answers. At the end of the survey, you will be provided a \$15 gift card.

**Is there any way being in this research could be bad for me?:** There is no health risk to taking part in the study. Some questions may be uncomfortable for you to answer. You do not have to answer any questions that you do not want to.

**Will being in this research help me in any way?:** There is no health benefit to you by taking part in the study. Your answers to the survey will be used to help researchers understand knowledge, perceptions and impact of eHealth and cancer literacy on your health, which will help inform how useful these questions are and how such knowledge might inform future literacy education for patients.

**What happens to the information collected for this research?:** Participation in this survey will not identify you though we cannot ensure absolute confidentiality. The IRB, Temple University, Temple University Health system, Inc. and its affiliates, and other representatives of these organizations may inspect and copy the information you provide on today's survey. All answers to the survey items will be recorded in the survey and each response will be labeled with an ID number, not your name or other identifying information. This information cannot be linked to

your name and your answers will not be shared. If you withdraw from the study, we will have your responses up to the point of you withdrawing.

**What will I be paid for taking part in this research?:** If you agree to take part in this research, you will receive a \$15 gift card at the end of the survey for your time and effort.

**What else do I need to know about this research?:** Taking part in this research study is your choice. If you decide to take part in this study, you may leave it at any time without cost or penalty to you. Not participating will have no effect on the care you are receiving.

**Federal Tax Statement:** *"Federal tax law requires you to report this payment as income to the Internal Revenue Service. You may be asked to tell us your social security number, full name, address, or other identifying information in order to compensate you for your participation. We may request this because we are required to report cumulative payments more than \$599.00, to the Internal Revenue."*

ID # \_\_\_\_\_

Patient Initials: \_\_\_\_\_

Consent: Yes/No

## eHealth Literacy, Coping Style and Cancer Literacy Outcomes Survey

<b>Before we begin we will ask you a few of questions to see if you are eligible to take our survey.</b>	
Have you received a cancer diagnosis?	Yes No Not sure
Are you currently getting treatment or follow-up care for your cancer?	Yes No Not sure
Are you 18 years or older?	Yes No

(You are eligible to take part in our survey if you answered "Yes" to cancer diagnosis, currently in treatment or follow-up care, and being 18 years or older.)

Thank you for agreeing to take our survey! Please let us know if you have any questions. Remember that **the answers you provide are confidential** and we won't be sharing your personal information with anyone else. We are hoping to understand how patients feel about finding health information online, what kinds of words related to cancer are familiar to you, and how you may be feeling about having cancer.

**The first set of questions are related to how confident you are understanding things related to having cancer. Circle the answer you think is right. If you aren't sure, guess which answer you believe might be correct.**

Item	Response format
1. The normal range for hemoglobin for a male is 13.3–17.2 g/dl. Joe's hemoglobin is 9.7 g/dl. Is Joe within the normal range?	a. Yes b. No
2. A biopsy of a tumor is done to ...	a. Remove it b. Diagnose it c. Treat it
3. If a patient has stage 1 cancer, it means the cancer is ...	a. Localized b. In nearby organs c. In distant sites
4. The role of a physical therapist is to talk to a patient about emotional needs.	a. True b. False
5. A tumor is considered "inoperable" when it cannot be treated with ...	a. Radiation therapy b. Surgery c. Chemotherapy
6. Sally will get radiation therapy once a day, Monday through Friday. If Sally has therapy for 4 weeks, how many times will she get radiation therapy?	a. 5 b. 15 c. 20

The next set of questions ask you to think about how you are feeling. Answer based on the answer that is closest to how you have been feeling in the past week. Don't take too long to answer each item: your immediate answer is the best. Please put a check mark next to your answer.

<b>In the past week...</b>
<b>I feel tense or 'wound up':</b>
a. Most of the time
b. A lot of the time
c. From time to time, occasionally
d. Not at all
<b>I get a sort of frightened feeling like 'butterflies' in the stomach:</b>
a. Not at all
b. Occasionally
c. Quite Often
d. Very Often
<b>I get a sort of frightened feeling as if something awful is about to happen:</b>
a. Very definitely and quite badly
b. Yes, but not too badly
c. A little, but it doesn't worry me
d. Not at all
<b>I feel restless, like I have to be on the move:</b>
a. Very much indeed
b. Quite a lot
c. Not very much
d. Not at all
<b>Worrying thoughts go through my mind:</b>
a. A great deal of the time
b. A lot of the time
c. From time to time
d. Only occasionally
<b>I get sudden feelings of panic:</b>
a. Very often
b. Quite often
c. Not very often
d. Not at all
<b>I can sit at ease and feel relaxed:</b>
a. Definitely
b. Usually
c. Not Often

d. Not at all

**Next, the following are descriptions of four situations. After each situation are statements that you may or may not do in that situation. Please mark Yes if you would do it or No if you wouldn't. Answer all the items for each scenario.**

- 1. Imagine that you are afraid of the dentist and have to get some dental work done. Which of the following would you do?**

I would ask the dentist exactly what he was going to do. Yes  No

I would want the dentist to tell me when I would feel pain. Yes  No

I would watch all the dentist's movements and listen for the sound of his drill. Yes   
No

I would watch the flow of water from my mouth to see if it contained blood. Yes   
No

- 2. Imagine that you are being held hostage by a group of armed terrorists in a public building. Which of the following would you do?**

I would stay alert and try to keep myself from falling asleep. Yes  No

If there was a radio present, I would stay near it and listen to the updates about what the police were doing. Yes  No

I would watch every movement of my captors and keep an eye on their weapons. Yes  No

I would make sure I knew where every possible exit was. Yes  No

- 3. Imagine that, due to a large drop in sales, it is rumored that several people in your department at work will be laid off. Your supervisor has turned in an evaluation of your work for the past year. The decision about lay-offs has been made and will be announced in several days.**

I would talk to my fellow workers to see if they knew anything about what the supervisor's evaluation of me said. Yes  No

I would review the list of duties for my present job and try to figure out if I had fulfilled them all. Yes  No

I would try to remember any arguments or disagreements I might have had with the supervisor that would have lowered his/her opinion of me. Yes  No

I would try to think which employees in my department the supervisor might have thought had done the worst job. Yes  No

4. **Imagine that you are on an airplane, thirty minutes from your destination, when the plane unexpectedly goes into a deep dive and then suddenly levels off. After a short time, the pilot announces that nothing is wrong, although the rest of the ride may be rough. You, however, are not convinced that all is well.**

I would carefully read the information provided about safety features in the plane and make sure I knew where the emergency exits were. Yes  No

I would call for the flight attendant and ask him/her exactly what the problem was. Yes  No

I would listen carefully to the engines for unusual noises and would watch the crew to see if their behavior was out of the ordinary. Yes  No

I would talk to the passenger beside me about what might be wrong. Yes  No

**\*The next set of questions are about how comfortable you are with technology and how useful you think getting health information is. eHealth stands for “electronic health” and can be information that you get about your health from the internet or information like a medical test result that is available to you from a healthcare institution through an online patient portal. It could also be services you get through your healthcare provider, such as “telehealth” visits. Please indicate how strongly you disagree or agree with each of the following statements. Please check only one box per statement by crossing it like this: ☒**

		Strongly Disagree	Disagree	Agree	Strongly Agree
1	I am sure that my health data...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	Using technology makes me feel...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	Information about my health is always available...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	I know how to use...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
5	The knowledge I have helps me to have...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	I know how to make technology...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7	I use technology to find...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8	I can enter data...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9	My healthcare providers deliver services that I can access...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10	My electronic healthcare data are being stored...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11	I often use technology to understand...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12	I have enough information to take part in...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13	Technology helps me decide...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14	I have a clear understanding of...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15	I understand medical results...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16	My health data are available...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17	I quickly learn how to...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18	I find that electronic Health (eHealth) systems...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19	I find technology helps me...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20	I use technology to share...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21	Overall, I understand how my body...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22	I am sure that only authorized people...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23	All the health technology I use works...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

24	I find I get better services...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25	I use technology to organize...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26	I use measurements about my body to...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27	Technology improves my communication...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28	I find eHealth systems seem to...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29	Most of my healthcare providers can be accessed...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30	I am confident that healthcare providers...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31	I find eHealth systems are provided to me in a way...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32	I easily learn to use...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33	eHealth systems provide me with easy ways...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34	I have access to health technology that...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35	I find technology useful...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

\*Items are truncated per permitted reproduction and adaptations by the Swinburne University of Technology eHealth Literacy Questionnaire's License Agreement.

**Finally, we'd like to ask you a little bit about yourself. This information helps us understand who is taking our survey.**

**1. What is your age? \_\_\_\_\_**

**2. What is the highest level of education you completed? (choose one)**

- No schooling
- Some grade school (less than 9<sup>th</sup> grade)
- Some High School
- High School Diploma/GED
- Vocational School
- Some College
- Graduated from College
- Graduate or Professional Degree
- Decline to Answer

**3. What kind of insurance do you have? (check all that apply)**

- Private, commercial insurance (i.e. HMO, PPO, etc.)
- Medicare
- Medicaid
- No insurance

- Not sure
- Other: \_\_\_\_\_

**4. What is your race?**

- White
- Black/African American
- Asian American
- American Indian/Alaska Native
- Native Hawaiian/Pacific Islander
- Other: \_\_\_\_\_

**5. Are you Hispanic? Latina/o/x?**

- Yes
- No

**6. What is your annual household income from all sources (choose one)**

- Less than \$10,000
- \$10,001 to \$25,000
- \$25,001 to \$50,000
- \$50,001 to \$75,000
- \$75,001 to \$100,000
- \$100,000 or greater
- Don't know
- Decline to answer

**7. What is your gender (check all that apply)**

- Man
- Woman
- Transgender Man
- Transgender Woman
- Gender Non-Binary/Non-Conforming
- Other: \_\_\_\_\_

**8. What is your marital status?**

- Married
- Single

- Separated
- Divorced
- Widowed
- Unsure/Decline to Answer

**9. Is this the first time you have been diagnosed with cancer?**

- Yes
- No

**10. What kind of cancer have you been diagnosed with most recently?**

---

**11. What stage of cancer do you currently have?**

- Stage 1
- Stage 2
- Stage 3
- Stage 4
- Unsure

**THANK YOU for completing our survey!**