Information Gathering to Improve Health Literacy and Understand Glaucoma

by

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Abstract

Glaucoma is a major cause of blindness among African Americans. There is currently a knowledge gap about glaucoma in the US population. The internet has emerged as a center of self-directed education in the 21st century. This study evaluated the trend in online search for glaucoma information and measured the readability of the information available to searchers. In addition, the ehealth literacy and knowledge of glaucoma of African immigrants in the United States were assessed.

Google Trend data showed an increase in search volume for glaucoma in the United States from 2006 to 2016 (slope of trend line = 0.085). Searchers were interested in the causes, nature, signs, predisposing factors, and treatment of glaucoma. Peak search periods for online glaucoma information correlated with news associated with celebrities diagnosed with glaucoma ($r = .57$, $p < .001$), new legislations, and announcement of new glaucoma drugs. Of the first 85 websites available to Google searchers during peak search periods, only 6 (7.1%) were from non-commercial sources. Glaucoma information was presented at grade level 11.75 (±1.50).

A total of 265 African immigrants aged 18 to >65 participated in this study. They had an average ehealth literacy score (eHEALS) of 30.94 out of 40. A multiple regression model showed the following as predictors of eHEALS: self-reported perception of online information as important, age, household income, frequency of internet search, and visiting a health care provider when sick. Surprisingly, educational level did not predict eHEALS; neither did the social media score, a measure of familiarity with social media.

Only 3% (8) of participants who completed the eye-Q test had scores above 9, the cut-off score for adequate glaucoma knowledge. A linear regression analysis of participants' scores on

eHEALS and eye-Q test indicated that 8.7% (r^2= .087, p<.001) of the variance in eye-Q test score is explained by eHEALS. Using multiple regression analysis, 28% of the variance (r^2 =.276) in the eye-Q test score was predicted by the following: gender, household income, employment status, age, eHEALS, and frequency of online search.

This study revealed that participants, despite their high level of education and eHEALS, were deficient in their knowledge of glaucoma. Online websites need to present glaucoma health information at levels easily understood by most consumers. Glaucoma education programs targeting African immigrants and other at-risk groups are urgently needed.

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CHAPTER 1

INTRODUCTION

Background

The health care system is complex and fragmented. A lot of responsibility is placed on patients in managing their own care. Individuals are constantly encouraged to become independent in their care, despite their limited knowledge of disease processes, patterns, and how their body works (Parker, 2000). They are expected to make decisions about their health and the care they receive from health care providers. In addition, they are challenged about making healthy lifestyle choices to prevent, manage and recover from illnesses. However, these individuals may not have the necessary skills required to access, understand, and use available health resources and information to improve their health (Zhang, Terry, & McHorney, 2014). When information is provided after a treatment, procedure or the diagnosis of a disease, it is often too technical and difficult to understand. Instructions about medication regimens, prevention and management of diseases are, therefore, hard to adhere to; they were not understood in the first place. This often leads to worsening health conditions, increased morbidity, decreased quality of life and, consequently, readmissions to the hospital. The rate of hospital readmissions is used to measure a hospital's performance in providing quality care to its patients. Readmissions within 30 days of hospital discharge cost the United States (US) approximately $17.4 billion annually. It has been shown that, to a major extent, the ability of patients to understand and make sense of the health information presented to them during their

illness and diagnosis of diseases, termed ‘health literacy’, impacts the probability of their readmission to the hospital after an initial visit (Bailey et al., 2015; Stevens, 2015).

Health literacy is defined as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health care decisions”(Ratzan & Parker, 2000, p. vi). The definition was based on the work carried out by Kickbusch and Nutbeam (1998, p.210) in which health literacy was defined as “the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information in ways which promote and maintain good health”. The World Health Organization (WHO) and the Institute of Medicine (IOM) have adopted this definition for health promotion programs in different parts of the world (WHO, 2018). The definition essentially advocates for individuals to have the mental capacity to critically think about the information they access and make healthy decisions and choices about their care (WHO, 2013). It is assumed that individuals are adequately capable of utilizing the information they obtain to make informed decisions about their health and healthcare.

Health literacy is strongly associated with the literacy level of an individual (WHO, 2013). The National Literacy Act (1991) defined literacy in the United States as “an individual’s ability to read, write and speak in English, and compute and solve problems at levels of proficiency necessary to function on the job and in society, to achieve one’s goals and develop one’s knowledge and potential” (GovTrack.us, 2020, p. 333). As a follow-up to the enactment of this act, Congress mandated the National Center for Education Statistics to assess the literacy of the US population. Thus, the National Adult Literacy Survey (NALS) was carried out in 1992. The survey defined literacy in three dimensions – prose, document and quantitative. The survey was designed to assess a set of information-processing skills used to accomplish specific day-to-

day literacy tasks. On the basis of the NALS, 14% of US adults (30 million) were shown to possess below basic literacy skills, 29% (63 million) had basic literacy skills, 44% (95 million) had intermediate literacy skills, while the remaining 13% (28 million) had proficient literacy skills. Individuals with proficient literacy skills can perform more complex tasks compared to those belonging to the other literacy levels (NAAL, n.d.). The survey was repeated in 2003 as the National Assessment of Adult Literacy (NAAL), along with questions that assessed other dimensions of literacy, including health literacy. The health literacy component of the NAAL showed that 43% of Americans have below or basic literacy skills and are more likely to have difficulties communicating with health care providers, interpreting medication instructions, and navigating the health care system (Bailey et.al., 2015).

In recent years, other tools have been used to measure health literacy. The most commonly used include the Test of Functional Health Literacy in Adults (TOFHLA) and the Rapid Estimate of Adult Literacy in Medicine (REALM) (Bailey et. al, 2015; IOM, 2013; Zhang, Terry & McHorney, 2014). The problem associated with these tools is that the results of their assessments are identical to basic literacy (reading ability and print literacy). It is therefore difficult to differentiate between the two. In addition, assessing the health literacy of individuals with limited English proficiency is difficult. However, health literacy is standardized to be measured using the national language of the country in which assessment is done. Hence, immigrants who are not able to read in the national language of their host country may be regarded as health illiterate in the country of residence (IOM, 2013; WHO, 2013). Literacy is also impacted by an individual's educational attainment (IOM, 2009; Sun et al., 2013).

Recent definitions of health literacy are moving away from honed skills to behavior change (Pleasant, 2011). According to Pleasant (2011), health literacy should be defined as a

theory that changes the behaviors of individuals and consequently their lives after making decisions based on information they acquire. While working as part of the "studying health literacy" project, Pleasant (2011) witnessed the effect of communication amongst the team members and solicited for the inclusion of effective communication in presenting health information to patients and the public with the aim of changing their behavior. Likewise, Ratzan (2001) suggested the inclusion of effective communication by healthcare providers in the development of health literacy since health information devoid of medical jargons and presented to patients in an easy to understand language may have a significant impact on the health literacy of patients. Thus, the source of health information may be a major determinant of health literacy.

Individuals often resort to the media for information on how to make sense of the health care system, their health and how to navigate the health care system. More recently, the advent of the internet and social media has dramatically expanded the sources of health information. In a Pew Research Organization study, Fox and Jones (2009) observed that 61% of adults in the US used the internet to search for health information. When the same study was conducted in 2013, Fox and Duggan (2013) reported that 59% of adults in the US looked online for health information within the 12 months prior to the study, while 35% of US adults indicated they used the internet to make a diagnosis of their medical condition. Likewise, Vogel, Perrin, Rainie and Anderson (2020) determined that 53% of Americans found the internet very crucial to their knowledge of the coronavirus a month into the coronavirus pandemic, while 34% of those who took the polls indicated it was an important tool in enhancing their knowledge. Approximately 77% of individuals looking for health information on the internet started their search using Google, Bing or Yahoo, while 13% used a health information site (Fox & Duggan, 2013).

Significance of the Study

There is an information gap between the public and health professionals. The professional community has not successfully changed its practices to communicate effectively with the public about their health. This has continually resulted in non-adherence to medication regimen, unhealthy lifestyle choices and decisions, deficit in self-management skills, increased hospital admissions and readmissions of individuals with chronic diseases. The health sector is more pragmatic than ever with the advent of increasing use of technology. Likewise, its users acknowledge their skill deficiency in health literacy and seek out ways to circumvent this. In addition, there is a paucity of understandable information available to individuals from the health care system to maintain health, coupled with the inability of health care professionals to explain diagnosis and treatments in a comprehensible way (Parker, 2000). Individuals have therefore resolved to rely on the internet and social media for information about health topics (Roberts, Callahan, O'Leary, 2017).

The internet and social media, consequently, play a major role in providing information about major health topics. However, the type, relevance, and accuracy of the information available is often questionable and have generated interest among researchers in recent years (IOM, 2013; Park & Conway, 2018). Several researchers have investigated the type and accuracy of online health information. Also, the flow and the frequency of flow of information have been studied. A major change associated with the emergence of the internet as an information source is the replacement of the top-down framing of issues and cueing of the public to a bottoms-up personal involvement in the generation of information (Bennett, Freelon, Hussain, & Wells, 2012). This participatory approach to online health information generation and consumption may

become important when considering diseases and health conditions that are more prevalent in certain segments of the population than others.

Glaucoma, a chronic eye disease that often leads to blindness is a topic that is not frequently discussed and may not receive a lot of attention in an online environment. If it is discussed, the accuracy of the information shared is questionable. Thus, an evaluation of the information shared on the internet about glaucoma is urgently needed. This will identify possible gaps in the information presented on the internet about glaucoma. It will provide possible recommendations and interventional strategies that will reduce the gaps identified.

Problem Statement

Health literacy, a major determinant of health, contributes immensely to the health outcomes of individuals and communities. It is an empowerment tool needed to navigate the fragmented and complex health care system with the desired outcome of healthy lifestyle choices and decisions, improved health, reduced hospital admissions and readmissions and reduced health care costs (Bailey, et.al. 2015; IOM, 2013; WHO, 2013). A quarter of the American adult population are functionally illiterate with a reading level of between eighth and ninth grade, despite an average educational attainment above the 12^{th} grade level (Parker, 2000). Also, a high proportion of the population scores in the lowest skill level on the practical everyday reading and numeracy assessment scale, which indicates possible difficulty in understanding health information (Parker, 2000).

Health information produced and provided at a level above the comprehension level of the public presents a self-management challenge to individuals (IOM, 2013; Parker, 2000). It is therefore necessary for health professionals, educational systems, policy makers and other stakeholders to work together to improve health literacy and reduce the complexities associated

with the communication of health information and the navigation of health care systems. The advent of the internet in recent decades has led to the democratization of health information. Although access to healthcare information has improved, the impact of public-sourced information on the overall health literacy of the population is still poorly understood (IOM, 2013). A better understanding of the interaction of users with the information obtained from the internet environment will help to structure health-information dissemination in a way that can significantly improve health literacy in the future.

Several researchers have investigated the type and accuracy of online health information (Benotsch, Kalichman & Weinhardt, 2004; Berland, et al., 2001; Storino, Castillo-Angeles, Watkins et al., 2016). Also, the flow and the frequency of flow of information have been studied (Hanna & Hanna, 2018; Harsha, Schmitt, & Stavropoulos, 2014; Hassid, et al., 2017). Glaucoma, a chronic eye disease, is the most common cause of blindness in the United States (National Eye Institute, n.d.). Epidemiological studies have demonstrated that this disease is most common among the Black population and individuals of African ancestry (Cook & Foster, 2012). However, there is paucity of information in the literature on how the internet is used as an online educational tool to understand this condition. If discussed, the accuracy of the information shared is questionable. Thus, it is necessary to conduct an evaluation of the information on the internet about glaucoma for possible gaps between who is seeking glaucoma information and what they want to know about the disease. The information presented on the internet needs to be evaluated for its educational value with the end goal of providing possible recommendations and interventional strategies that will reduce gaps in knowledge concerning glaucoma, and consequently the self-management of the disease.

Purpose of the Study

It has been estimated that the prevalence of glaucoma in African Americans ranges from 4% in people aged 50 – 59 to 13% in those aged 80 – 89 years old. These rates are consistently higher than the 2% - 3% prevalence rate reported among equivalent age groups in the general population of the United States (Tielsch, Sommer, Katz, Royall, Quigley & Javitt, 1991). It has therefore been suggested that individuals of African ancestry may carry a genetic predisposition to glaucoma (Racette, Wilson, Zangwill, Weinreb, & Sample, 2003). The past decade has seen a dramatic increase in the number of African immigrants to the United States; they now constitute about 5% of the US population (Anderson, 2017; Omenka, Watson, & Hendrie, 2020). A study in Minnesota, where African immigrants now constitute approximately 2% of the state's population have suggested that this group may face impediments that include language barrier and difficulty in navigating the healthcare system (Cernasev et al., 2020), suggesting a low health literacy among African immigrants compared to the general population of the United States. The health literacy of African immigrants in the United States has not been extensively studied, neither has their use of the internet as a source of health information previously explored.

Thus, the purpose of this study was to evaluate the ehealth literacy of African immigrants living in the state of Missouri, evaluate their use of the internet and social media as information source, and determine the factors that may predict their knowledge of glaucoma. Additionally, this study will determine the trend of online information search about glaucoma over a period of 10 years from 2006-2016, identify the triggers of observed surges in glaucoma information search, and evaluate the quality of the information available to online information seekers during each surge in the search for glaucoma information.

Research Questions

To achieve the stated goals of the study, the following specific research questions were used:

1. What type of glaucoma information do individuals search on the internet using the google search engine?
2. What is the trend of online search for glaucoma information using google over the 10-year period from 2006-2016?
3. What are the triggers for an increase in online search for glaucoma when spikes in searches were observed from 2006-2016?
4. What is the health educational value of the information materials available during a surge in online google search for glaucoma over the period studied from 2006 to 2016?
5. What are the factors that predict the ehealth literacy of African immigrants in the state of Missouri?
6. Does ehealth literacy predict the knowledge of African immigrants about glaucoma?
7. What factors will predict knowledge about glaucoma in African immigrants in the state of Missouri?

Definition of Terms

eHealth literacy. 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 & Skinner, 2006).

*Glaucoma***.** This is a group of eye diseases that cause vision loss and consequently blindness by damaging the optic nerve that is responsible for transmitting visual information from the retina to the vision centers of the brain. Glaucoma is a chronic eye disease. It is the most common cause

of blindness in the United States (National Eye Institute, n.d.). Epidemiological studies have demonstrated that this disease is most common among the Black population and individuals of African ancestry.

Health Information Seeking Behavior (HISB). It is the characteristic that influences the ways in which individuals search for information about their health, how to protect themselves from illnesses, improve their health and stay healthy (Jacob et al., 2016). In practice, it describes the active, planned and purposeful process of seeking for health information. It is an essential attribute that allows an individual to remember the information gathered when needed for use in health decision.

Health literacy. The definition of health literacy adopted in this study was the definition given by Ratzan and Parker (2001). Health literacy was defined as the "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (p. vi).

Literacy. For the purpose of this study, literacy is defined as the ability of individuals to read, write, understand, interpret, communicate, compute and solve problems at proficiency levels needed to achieve personal goals and develop potentials (UNESCO, 2018; Public Law, 1991).

Readability. This is the ease with which a text material is read and understood. The readability of a text is determined by the length of sentences, the number of sentences and the complexity of the words in the text. The word complexity of a sentence is influenced by the average number of syllables per word. Several research-validated tools are available for the evaluation of the readability of texts.

Organization of the Study

This study was divided into five chapters. Chapter 1 introduces the study by discussing the background information of the study, significance of the study, the statement of the problem, purpose of the study, research questions, and the definition of terms. Chapter 2 presents a review of the literature. The review is organized into eight sections: health literacy, literacy, measurement of health literacy, ehealth literacy, health information seeking behavior, management of chronic diseases, self-directed learning, and a brief discussion about glaucoma. Chapter 3 gives an account of the methods utilized in the study. It encompasses the sampling method used, the sample, instrumentation, and the plan of data analysis. Chapter 4 presents the results of this quantitative study. The analyses of the data collected in this study are used to provide responses to the research questions started with at the beginning of the study. Lastly, Chapter 5 presents a discussion of the study findings, conclusions of findings and the summary of findings. In addition, it presents the limitations of the study and provides recommendations for improving the dissemination of online patient educational materials. This section also provides recommendations for future research.

CHAPTER 2

LITERATURE REVIEW

This chapter presents a review of the literature. The review is organized into eight sections: health literacy, literacy, measurement of health literacy, ehealth literacy, health information seeking behavior, management of chronic diseases, self-directed learning, and a brief discussion about glaucoma.

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Health Literacy

Inadequate health literacy has been associated with increased hospital admissions, readmissions, poor health outcomes, non-adherence to medication, non-compliance to a treatment regimen, disease complications, decreased quality of life, and increased hospital spending (Bailey et al., 2015; Hansen, Williams & Singer, 2011; Institute of Medicine, 2013; Paasche-Orlow & Wolf, 2007; Parker, 2000; Ratzan, 2001; World Health Organization (WHO), 2013). Disparities in the health outcomes of communities have also been linked to differences in health literacy. Individuals with a high level of health literacy are more likely to have better health outcomes than those with low levels (Bailey et al., 2015; Parker, 2000). Poor health outcomes of individuals result in increased morbidity and consequently increased mortality, leading to increased cost for the health care system (Bailey et al., 2015). It has been established in the literature that "lower educational attainment, racial/ethnic minority status, older age, lower income, and recent immigration to the U.S. were associated with lower health literacy" (Martin et al., 2009, p. 1214). For the purpose of this literature review, the various definitions of health literacy will be considered, the implications of the definitions, the improvement in health literacy over the years, the various tools for measuring health literacy, electronic health literacy, adult literacy and literacy will be considered, before looking at the various methods that have been used in predicting the online information seeking behavior of adults.

Health Literacy Defined

Health literacy is an evolving construct. The term was first used in 1974 to describe health education that meets minimal standards for all school grade levels (Ratzan, 2001; Simonds, 1974). This confirms its root in school health education targeted at improving children's health literacy and, subsequently, adult health literacy (Okan et al., 2018). Health

literacy has been defined in different ways by different researchers and authors. Also, the term has stirred up a lot of debate and research to enhance its understanding in a way that promotes health and quality of life (Baker, 2006; Berkman, Davis, & McCormack, 2010). There have, therefore, been many definitions, without a consensus on the accepted one. However, a consistent theme in the different definitions is the need for the acquisition of skills in order to attain an improved health status (Freedman et al., 2009).

The *ad hoc* Committee on Health Literacy (1999) in a report for the council on scientific affairs defined health literacy as "a constellation of skills, including the ability to perform basic reading and numerical tasks, required to function in the health care environment" (p. 553). Greenberg (2001) contended that the inclusion of numeracy in the required skills needed to achieve health literacy is an advantage of this definition. Numerical skills are critical to the understanding of health information and the interpretation of results of measurements related to health; examples are blood pressure, blood glucose readings, temperature, and amounts of medications to be taken. However, Greenberg (2001) also suggested that this definition is not sufficient as it puts the full responsibility on the individual while neglecting the role of health care professionals and the health care system in improving health literacy. Furthermore, Greenberg (2001) asserted that cultural beliefs and receptive and expressive skills of communication should have been included in the definition. These communication skills, he emphasized, are vital for productive navigation of the health care system (Greenberg, 2001). The *ad hoc* Committee on Health Literacy (1999), on the other hand, explained that based on their definition, health literate individuals should be able to read, understand and make use of health information.

Ratzan and Parker (2000) defined health literacy 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’’(p. vi). This was the definition adopted by the Institute of Medicine (IOM) and for Healthy people 2010 (IOM, 2004). This definition refers to the ability of the individual based on skills and innate potentials that are largely affected by the individual’s growth environment, upbringing, exposure, socioeconomic status (SES), language, culture, religious beliefs, and values (IOM, 2004; Pressley & McCormick, 2007). However, Berkman and his colleagues modified this definition into “the degree to which individuals can obtain, process, understand, and communicate about health-related information needed to make informed health decisions” (Berkman et al., 2010, p. 16). This modification of Ratzan and Parker’s definition, according to Berkman and colleagues, shifted the emphasis of health literacy to the possession of skills and abilities needed by individuals and the health care system to achieve set health outcomes (Berkman et al., 2010).

In addition, Parker (2009) during the roundtable workshop on measures of health literacy, defined health literacy as the ability to understand the information presented on health issues. Communication, according to Parker (2009), is a major part of health literacy; how an individual perceives the health information presented, determines how the information will be used, and how it will impact the life of the individual (Parker, 2009). The IOM further used the definition of health literacy espoused by Ratzan and Parker (2000) to explain health literacy as a balance between what an individual seeks for and what is provided by health care professionals (IOM, 2004). Health literacy is, therefore, determined by a milieu that includes educational attainment, health care system, socioeconomic status, and the cultural disposition of the individual (IOM,

2004). It is a result of the interaction between individual abilities and the milieu of existence (IOM, 2004; Rudd, 2003).

Nutbeam (2000), in addition to the other definitions, introduced the importance of possession of cognitive and social skills that influence an individual's ability to use health information in order to promote health. Conversely, Freedman et al. (2009) argued that the definitions are limited to the abilities and competencies of individuals when it should have been defined as an interaction of factors between the individual and the health care system. This statement by Freedman and his colleagues was in consonance with what Parker proposed during the workshop on measurements of health literacy. Parker (2006) proposed that for individuals to be health literate, their skills and abilities must meet the demands and complexities of the health care system.

Freedman et al. (2009), in explaining their position, proposed a more comprehensive definition of health literacy that comprises both the individual and the public. These authors insisted that a definition of health literacy that excludes the community or public is not capable of achieving ultimate health outcomes. Thus, Freedman et al. (2009) advocated for public health literacy as opposed to individual health literacy. They argued that public health literacy is more encompassing than individual health literacy. Freedman et al. (2009), therefore, proposed a definition which emphasized the ability of the individual and the community to access and use health information for the improvement of health outcomes. Hence, health literacy was "the degree to which individuals and groups can obtain, process, understand, evaluate, and act upon information needed to make public health decisions that benefit the community" (Freedman et al., 2009, p. 448).

A more comprehensive and more encompassing definition was developed by Sorensen and his colleagues (2012) after carrying out a systematic review of the literature. The researchers, based on their examination and review of 17 articles defined health literacy as "knowledge, motivation and competences to access, understand, appraise and apply health information in order to make judgements and take decisions in everyday life concerning health care, disease prevention, and health promotion to maintain or improve quality of life during the life course" (Sorensen, et al., 2012, p. 3). This definition is applicable to individuals as well as the public in the prevention of diseases and promotion of health. The World Health Organization (WHO) and the European Union adopted this definition in 2012 to carry out Health Literacy Survey in Europe (HLS-EU Consortium, 2012).

Literacy

Becoming health literate is a growing challenge with the complexity of the health care system and technological discoveries and advancement (IOM, 2004). Health literacy is dependent on and linked to an individual's literacy status and abilities in the presence of socioeconomic factors that affect the health of the individual (IOM, 2004; WHO, 2013). Health literacy is therefore regarded as "the bridge between literacy skills and abilities of the individual and the health context" (IOM, 2004, p. 32), where literacy equips the individual with skills needed to express themselves and understand received information (IOM, 2004)

Literacy can be traced back to 3500 BC when the first written communication was produced and the few people who were able to read and write displayed their skill in public performances. The first known books were found in Rome around 23 BC; widespread availability of books did not occur until the invention of the Guttenberg printing press in the 15th century. In the United States, literacy dates back to the early settlers, specifically the Puritans,

who were greatly interested in knowing how to read the bible to improve their faith. The children in this era did not go to school to be literate. They learned to read the bible and developed knowledge about their society and how to live from their parents and preachers (Cohen & Kisker, 2009). At that time, literacy was measured by the ability to sign documents or will at the time of death (Lockridge, 1974). As a result of this, literacy grew slowly until the industrial revolution when the production of paper was increased. This subsequently led to a reduction in the cost of book production. At about the same period, the concept of universal literacy was introduced to US public education (Lockridge, 1974, Roser & Ortiz-Ospina, 2018).

Low literacy is a world-wide problem. It is estimated that one in every five individuals is illiterate. Much of the population in about 27 nations of the world are illiterate with their literate rate below 50%. However, the Institute for Statistics under the United Nations Educational, Scientific and Cultural Organization (UNESCO) estimated a worldwide literacy rate of 86.5% for individuals above the age of 15, based on self-reported data from countries of the world. These individuals were able to read, write and understand simple statements related to their everyday life. (UNESCO Institute for Statistics, 2019). However, there are countries with low literacy levels. An example is Burkina Faso, a country in sub-Saharan Africa, had an adult literacy rate of about 41% in 2018 (Roser & Ortiz-Ospina, 2018). There has been a great deal of focus on eradicating illiteracy and facilitating education in different countries of the world. To enable this, after World War II, the UNESCO was set up in 1946, to rebuild schools, libraries, and museums that were destroyed in Europe (Mingst, 2018). In fostering literacy and increasing the global empowerment of individuals, UNESCO put several initiatives in place and sponsored many literacy programs. One of its programs was the International Plan of Action for the

Eradication of Illiteracy before the year 2000. This program facilitated the integration of literacy into every educational program and process in member countries (Ouane, 2009).

Literacy in the United States has improved over the years, especially after the National Adult Literacy Surveys (NALS) were conducted in 1992 and 2003 to assess the literacy of adults in the US. The study revealed that a large segment of the population of the country had limited literacy skills and highlighted the implications of high levels of illiteracy on the nation. Consequently, the definition of literacy changed from what can be achieved based on years of schooling to a more concrete definition that captures the effective role of literacy in acquiring knowledge and skills to achieve individual goals (Kirsch, 2003). The Institute of Medicine (IOM, 2004) defined literacy as the ability to carry out daily tasks of reading printed materials and verbally communicating with other people using the acquired skills of reading, writing, speech comprehension, and numerical calculations (IOM, 2004).

Similar to the definition given by the IOM in terms of utilizing abilities, the National Literacy Act (NLA) defined literacy in the United States as "an individual's ability to read, write, speak in English, and compute and solve problems at levels of proficiency necessary to function on a job and in society, to achieve one's goals and develop one's knowledge and potential" (Public Law, 1991, p. 105 STAT. 333). This definition of literacy was used in the development of the NALS which was subsequently used in the national assessment of adult literacy (NAAL) in the US (IOM, 2004). NALS defined literacy as the ability of individuals to "use printed and written information to function in society, to achieve one's goals, and to develop one's knowledge and potential" (Kirsch, 2001, p.6). UNESCO provided a broader definition of literacy as "the ability to identify, understand, interpret, create, communicate and compute, using printed and written materials associated with varying contexts" (Montoya, 2018, slide 1).

Assessing Health Literacy

From the various definitions of health literacy, it is evident that the concept is broad and extends beyond the skills and abilities of an individual. It depicts the symbiotic relationship that exists between the individual and the health care system; individuals benefit from the health care system after overcoming the barriers and obstacles associated with accessing the system (Parker, 2009). To adequately determine the ability of individuals to benefit from the health care system, the tool used to assess health literacy must be one that is based on an interaction of the various factors involved in the achievement of health outcomes (IOM, 2009). The various tools developed for the measurement of health literacy were based on the model proposed by Pasche-Orlow and Wolf (2007) where the focus was on the abilities of the individual in improving health outcomes while neglecting the interaction that takes place between the individual abilities and the complexities of the health care system (IOM, 2009). The different tools developed are based on different underlying assumptions of health literacy; hence, the difference in the various tools and what they measure.

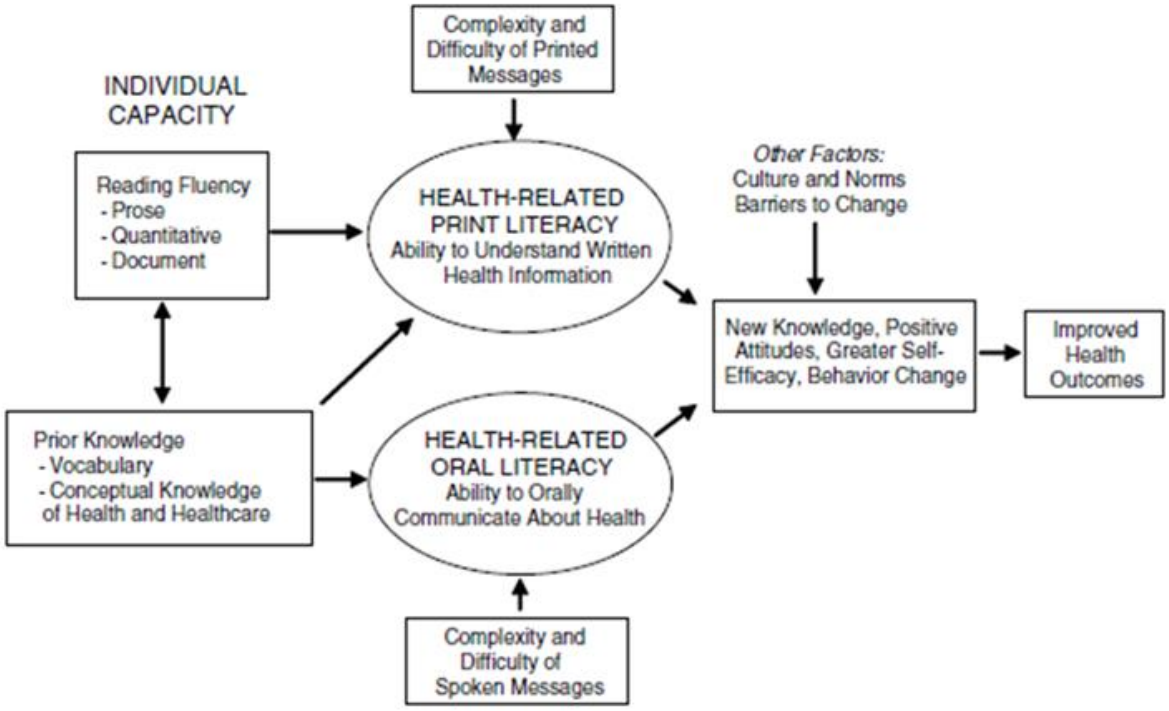
With the focus of most assessment tools on individual capacity, Baker (2006) suggested the need for a health literacy measurement tool that can assess the reading ability and vocabulary of an individual. Furthermore, he maintained that the development of appropriate tools for assessing health literacy is crucial for the adequate measurement of health literacy. This, he emphasized, allows for appropriate interventional strategies targeted at improving health literacy and subsequently health outcomes. Baker (2006) proposed and advocated for a consensus on a conceptual model, Figure 1, that can facilitate the assessment of health literacy in practice and research. Using the model, Baker (2006) suggested that the best way to measure health literacy is by evaluating the incongruity or mismatch that exists “between the individuals' reading fluency,

vocabulary, background knowledge, and their oral and written communication demands" (p. 880).

Figure 1 presents health literacy as an interaction between the competencies of the individual and the complexity of the health care system in which the individual operates. The model identifies the important role of background knowledge in the processing and understanding of the various forms of health information presented by health care providers. Adequate understanding of the presented health information is crucial for the construction of new knowledge about health, and subsequently a change in attitude and behavior that is required for improved health outcomes (Baker, 2006).

Figure 1

"*Conceptual model of Health Outcomes Relationship".*



(Baker, 2006, p. 879)

The different tools that have been developed based on different conceptualizations of health literacy include but are not limited to the health literacy component part of the National Assessment of Adult Literacy (NAAL). Other assessment tools include but are not limited to the Rapid Estimate of Adult Literacy in Medicine (REALM), the Test of Functional Health Literacy in Adults (TOFHLA), the Health Activities Literacy Scale (HALS), the Newest Vital Sign (NVS), the single (or three) item screeners, the Short Assessment of Health Literacy for Spanish-speaking Adults (SAHLSA), the Stieglitz Informal Reading Assessment of Cancer Text (SIRACT), the Wide Range Achievement Test (WRAT), the Medical Achievement Reading

Test (MART), the Functional Health Literacy Measure (FHLM), and Health literacy screener (ELF) (IOM, 2009). Though these tools assess certain aspects of individuals' capacity, they do not give a complete assessment of an individual's ability. The two most widely used health literacy assessment tools are the REALM and TOFHLA (Baker, 2006; IOM, 2009).

The REALM is an assessment tool that examines the individual's ability to recognize words by correctly pronouncing 66 words that are commonly used in the health care system (Bailey et al., 2015; Baker, 2006). A shortened version of the instrument was developed by Davis et al. (1993) to assess health literacy in one to two minutes. The administration of this instrument is cheaper and the tool is easier to use; skilled personnel are not required (Davis et al., 1993). In addition, the REALM-teen was developed for use in children. It was the first health literacy assessment tool used in children (Davis et al., 2006).

The TOFHLA was developed to assess how individuals are likely to interact with the health care system. The tool uses a 50-item written instruction to evaluate reading comprehension and a 17-item numerical test. The tests take about 22 minutes to administer (Bailey, 2015; Baker, 2006; Parker, Baker, Williams, & Nurss, 1995). A version for use in teenagers, TOFHLAd, was also developed (Okan, 2018). A comparison of TOFHLA and REALM showed a positive correlation with a correlation coefficient of 0.84 (Baker, 2006; Parker et al., 1995). Similarly, TOFHLA and REALM correlate with the revised Wide Range Achievement Test (WRAT-R). TOFHLA has been found to be applicable and reliable in the clinical and research setting (Parker et al., 1995). There is a short version of the tool and a Spanish version (for use in the Spanish population). These are referred to as the S- TOFHLA and the TOFHLA-S, respectively (Baker, Williams, Parker, Gazmararian, & Nurss, 1999; Parker et al., 1995).

For a more inclusive assessment tool, the Health Activities Literacy Scale (HALS) was developed, to examine the relationship between health and literacy. Health-related tasks on the NALS were used to develop the HALS (Rudd, Kirsch & Yamamoto, 2004, University of Boston, 2018). The score on the test ranges from 0-500 on a 0–5 point scale. The test takes about 30-40 minutes to complete (Baker, 2006; University of Boston, 2018). The HALS could be administered either face-to-face, or through a computer-based program. Individuals are categorized as intermediate, marginal, or adequate, based on their score on the test.

The NAAL was developed for use in assessing health literacy in American adults. This tool, though not publicly available, measured health literacy directly by giving adults tasks to perform (IOM, 2009). The health literacy tasks were daily tasks encountered by adults as they carry out their daily activities. They were everyday literacy tasks of prose, document and quantitative literacy. Health and health care information questions were incorporated into the literacy tasks to assess the health literacy of respondents (Kutner, Greenberg, Jin & Paulsen, 2006, pp. iv). When the tool was used on adults in the US in 2003, the results of the survey revealed that 53 percent of American adults had *Intermediate* health literacy, 12 percent had *Proficient* health literacy, 22 percent had *Basic* health literacy, and 14 percent had *Below Basic* health literacy (Kutner et al., 2006). These results showed that 36% of the population had limited health literacy and were unable to effectively navigate the health system or care adequately for themselves (Mika, Kelly, Price, Franquiz, & Villarreal, 2005).

Another assessment tool that has been used in determining the health literacy levels of individuals is the NVS. The NVS is a short assessment tool that was created by Weiss and his colleagues (2005) in an attempt to overcome the disadvantage of prolonged time associated with other measurement tools. The tool consists of six questions which can be completed in three

minutes to determine limited literacy. It is a reliable tool and correlates well with the TOFHLA (Weiss et al., 2005). This tool is also available in Spanish.

Electronic Health Literacy (eHealth Literacy)

The health literacy scales discussed so far are mainly focused on print; none are targeted at electronic sources. With increase in the availability and use of electronic health information and services in recent years, there is a shift in emphasis towards electronic health (ehealth) to improve health outcomes (Eng, 2001; Eysenbach, 2001). Navigating and accessing electronic health resources requires skills and abilities to overcome the complexities and barriers associated with the use of the internet and other ehealth tools (Chan & Kaufman, 2011; Giustini, 2006), that extend beyond what is required for printed health resources. Individuals must have the technological know-how to operate the computer, locate accurate information and interpret the information in a way that helps them achieve health goals and outcomes (Norman & Skinner, 2006). This competence, known as ehealth literacy, is 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" (Norman & Skinner, 2006, p. 2). Norman and Skinner (2006) acknowledged the dynamic nature of ehealth literacy in a dynamic health care system with new discoveries and innovations in technology. Therefore, they proposed a model using the metaphor of a lily to explain the essential competencies of ehealth literacy required by individuals to meet health needs. The petals of the lily are synonymous to "traditional literacy, health literacy, information literacy, scientific literacy, media literacy, and computer literacy", which are connected together, giving rise to the capacity of the individual ("pistil") to achieve optimal health outcomes using e-health resources" (Norman & Skinner, 2006, p. 2).

Several definitions were proposed that built on Norman and Skinner's definition (Paige et al., 2018). These definitions, according to Paige et al. (2018) and Mackert et al. (2014), lacked theoretical underpinnings; hence limiting their applications. Mackert et al. (2014) suggested the need for a theoretical foundation for proposed models and definitions of ehealth literacy. The authors advocated for health literacy models, communication theories, and theories governing information systems to be incorporated into ehealth literacy models and definitions (Mackert et al., 2014). Paige et al. (2018) therefore proposed a definition based on the transactional model of communication in which ehealth literacy is viewed as a dynamic intrapersonal concept operating in a transactional environment where undesirable variables referred to as noise exist. After a review of ten definitions of ehealth literacy, Paige et al. (2018) proposed a new definition that improved the contribution of communication to ehealth literacy compared to definitions before it. The new definition incorporated the context of the Transactional Model of Communication (TMC). Electronic health literacy was therefore defined as "the ability to locate, understand, exchange, and evaluate health information from online environments in the presence of dynamic contextual factors and to apply the knowledge gained across ecological levels for the purposes of maintaining or improving health" (Paige et al., 2018, p 17).

The search for health information online is one of the most popular activities online users engage in. However, there is an increasing concern that individuals may not be able to adequately evaluate the quality of the provided information. Several studies have therefore been conducted to determine the factors that predict that an individual have the competencies to source for accurate and quality health information online. Stellefson, Hanik, Chaney, Chaney, Tennant, and Chavarria (2011) carried out a systematic review of studies from 2000 to 2010 on college students who were between the ages of 17 and 26, enrolled in a 4 year program to

evaluate the ehealth literacy levels of this group. The results of their review indicated that many college students lack ehealth literacy skills. Three of the studies reviewed by these authors indicated there was no congruence between the students' perceived ehealth literacy skills and their actual ehealth literacy skills. Other studies have indicated that lower levels of education were associated with lower levels of ehealth literacy (van Deursen, 2011), while others have shown that levels of educational attainment do not correlate with ehealth literacy (van der Heide et al., 2013). There are conflicting results from different studies on the various factors that determine adequate ehealth literacy.

Norman and Skinner (2006) developed an ehealth literacy scale (eHEALS) to measure consumers' perceived skills at locating, evaluating and applying electronically available health information to solving health problems. This ehealth literacy scale has been widely used to measure consumers' perceived skills at locating, evaluating and applying electronically available health information to solving health problems (Norman & Skinner, 2006). The scale is an eight-item tool that combines individuals' health literacy skills with their ability to use the computer. The tool is reliable and easy to administer (Vander Vaart, Deursen et al., 2011). It has been used in several studies (Brown & Dickson, 2010; James & 2016; Norman & Skinner, 2006; Robinson & Graham, 2010).

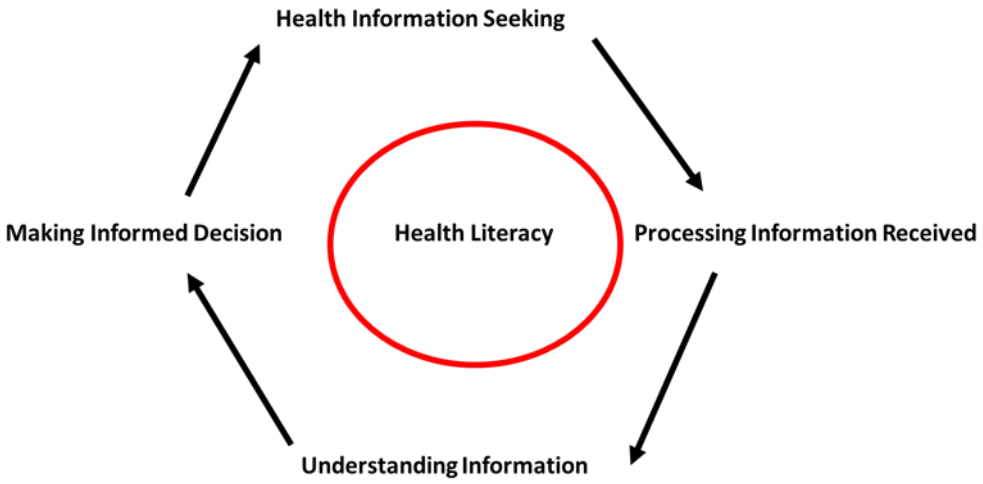
Health Information Seeking Behavior

The definitions of health literacy given by Ratzan and Parker (2000) and Berkman and colleagues (2010) emphasized the possession of skills to find or search for health-related information, which is the ability to seek for health information from various sources. Embedded in the definitions of health literacy is the ability of the individual to search for health-related information for empowerment in the health care process. This makes health information seeking

(HIS) an important first component of health literacy. From the definition of health literacy, a flow diagram that shows HIS as the first component of health literacy is shown:

Figure 2

Health information seeking (HIS) as an important process in health literacy



Information seeking, according to Niederdeppe et al. (2007), is an active and purposeful search of information to obtain stability after an event or occurrence has led to instability. It is a focused search for information for later recall to facilitate the process of decision-making. It is intentional and goal oriented. The sources mostly used are the ones that are readily available, easily accessible and easily navigated by individuals. Health information seeking, therefore, is an active, planned and purposeful process of seeking for health information predominated by the health information seeking behavior (HISB). It is associated with detailed remembrance of information and use of information in decision-making (Niederdeppe et al., 2007).

HISB is the characteristic that influences the ways in which individuals look for information about their health, how to protect themselves from illnesses and improve their health (Jacobs et al., 2016). The characteristics are the variables that interact to stimulate an individual

to seek for information about their health. These variables according to Anker, Reinhart and Feeley (2011) include the intricacies of the individual, "the environment, context, current events, and the search process" (p. 347). This indicates that HISB is not only dependent on individual characteristics like gender, race, socioeconomic (SES) status, education, income, age, and health literacy, but also on factors within which the individual operates (Anker et al., 2011).

Various studies have examined the characteristics that influence the information seeking behavior of an individual. Arora et al. (2008), used the Health Information National Trends Survey (HINTS) data to determine the characteristics of the individuals that seek for cancer information. The results of the investigation indicated that women, age younger than 65 years, and high levels of education are characteristics that predict that an individual would likely seek for cancer related information. Another study conducted by Bhandari, Shi and Jung (2014) using the National Health Interview Survey (NHIS) data collected in 2009, showed that individuals who sought for health information online, tend to be younger, are college educated, have higher incomes, and report better health. From the two studies, age, gender and education seem to be the main sociodemographic variables that influence the search for health information by an individual.

In seeking for health information, individuals consult with health care professionals, books, print and mass media, and the internet (Jacobs, Amuta, & Kwon, 2017). The internet has, however, been more widely accessed in recent years for health information compared to other sources due to its ubiquity, versatility, lower cost, and anonymity (Cline & Haynes, 2001; Tennant et al., 2015; Jacobs et al., 2016). Health information online is available in the form of bulletin boards, blogs, social networks, chats with physicians, and peers in a network community, and email communications with physicians and other health professionals (Bhandari

et al., 2014). The many barriers to health care facilities and, consequently, health care professionals have fostered the use of the internet in the search for information relating to chronic conditions or disease state (Arcury et al., 2005; Bisgaier et al., 2011; Decker et al., 2012). Often, individuals consult the internet to understand or consolidate confusing or difficult to understand health messages from health care professionals (Jacobs et al., 2013; Parker, 2000). Many individuals do not use one source as their only channel but use a combination of sources to help them in making appropriate health decisions (Bhandari et al., 2014; Jacobs et al., 2013). These have propelled the use of the internet above the use of health care professionals and family members, which are the other top two information channels for health information (Fox & Duggan, 2013; Jacob et al., 2013).

In determining the factors that will predict if an individual will use either the internet, family/friends, health care provider or the traditional media in their search of health information, Jacobs and colleagues (2016) directed an investigation to examine these factors. The researchers investigated factors like internet skills, health status, overall health perception, family history of cancer, SES, and individual factors to determine if they would predict that an individual would seek for health information from a particular source or not. HINTS data collected from 2011 to 2014 was used in the study. The study indicated that individuals with high internet skills were more likely to use the internet as their source of health information than any other source. These individuals were of a younger age, high educational level, and high socioeconomic status. In addition, the study showed that being older, Hispanic, and having low internet skills are determinants of seeking health information from healthcare professionals and from the traditional media like the print media, radio or television. Having a lower SES predicted the use of traditional media as a source of health information. Being male, Hispanic and having a family

history of cancer predicted that an individual would seek health information from health care professionals. The survey recruited mainly whites and female participants, which limits the generalization of the study to other population groups.

With the prevalence of the internet for health information has come the use of the internet in making personal diagnosis of diseases, treatment and management of diseases, active participation in the care process and, at times, non-adherence to medication regimen or treatment (Fox & Duggan, 2013). Individuals accessing online health information must be able to evaluate the information for accuracy, authenticity and completeness. The ability to evaluate online health information is dependent on the health literacy of the individual (Benotsch, Kalichman, & Weinhardt, 2004; Tennant et al., 2013). The National Assessment of Adult Literacy Survey, however, revealed that a significant portion, 36% of the population have difficulty evaluating the health information received from the internet or other health information sources.

Benotsch, Kalichman, and Weinhardt (2004) investigated the ability of adult patients with HIV to accurately evaluate online health information relating to their illness. The results of the study showed that individuals with low health literacy did not accurately evaluate the quality and credibility of health information websites compared to individuals with high health literacy who accurately evaluated the health information websites. In addition, a qualitative study carried out by Rennis, McNamara, Seidel and Shneyderman (2010) on 14 college students who accessed the internet for information on self-care strategies and alternative therapies indicated that the students did not have the skills to adequately evaluate the websites accessed for authenticity and completeness of information. The generalization of this study is questionable due to the sample size and the research method used. A systematic review of the literature conducted by Diviani et al. (2016) did not support the claim of these researchers based on the quality of studies retrieved

for the review. They advocated for more work to determine the true relationship between health literacy and accurate evaluation of online health information websites and the information they provide. If health decisions that will affect health outcomes are made based on the health information received from the various sources, individuals have to be able to evaluate the information accessed in order to make accurate decisions.

Studies have also shown that self-efficacy and health anxiety are factors that explain health information seeking behavior in individuals (Eastin & Guinsler, 2006). A study carried out by Shieh and Stump (2010) established that self-efficacy is an important factor in health information seeking. Self-efficacy in information seeking determines the motivation and confidence with which an individual seeks for health information. It is also a crucial factor in predicting the accurate use of the information obtained in the management of one's care. The authors examined the effect of self-efficacy, health literacy, and fetal locus of control on the health seeking behavior of pregnant women. 143 pregnant women were recruited to the study from a prenatal clinic and the Health Information Competence Scale (HICS), developed by Gustafson et al. (2005), was used to measure self-efficacy related to information seeking. The researchers gathered from the study that self-efficacy was correlated to the HISB of pregnant women. However, the study failed to show that the health literacy of the pregnant women was associated with their health information seeking.

In determining the other characteristics that predispose individuals to seeking information about their health, researchers like Dehkordy, Carlos, Hall and Dalton (2014) examined the information seeking behavior of women relating to their screening behavior in terms of breast health. The researchers accessed the online search for dense breast, to determine the extent of search on the internet using the google search engine. The data obtained from google trend were

correlated with news coverage and the introduction/passage of dense breast notification legislation. The results of the study indicated that there was an increase in information seeking about dense breasts when there was an increased news about legislative action (Dehkordy et al., 2014). These researchers gathered from the investigation that "legislative activity, whether proposing a bill or even defeat of a bill, and associated news coverage, ……. correspond with trends in increased information seeking about dense breasts, thus suggesting that legislation may be a potential driver of information seeking" (p. 4).

Likewise, Niederdeppe and colleagues (2008) investigated the relationship between the coverage of cancer on the news and the rate at which individuals seek for cancer related information after the news. To investigate this relationship, the researchers used the Health Information National Trends Survey (HINTS) data and data describing the Associated Press (AP) news coverage of cancer. HINTS is a representative national survey conducted by the National Cancer Institute (NCI). The AP news is a wire service that covers a wide variety of news items. About 85% of American newspapers utilize the services provided by AP news. The HINTS survey recruited 6,369 adults through a random digit dialing (RDD), from age 18 and above to participate in the study. The researchers combined the data from HINTS with the data describing AP news coverage of cancer over a period of 6 months, from October 21, 2002, through April 13, 2003. In this study, the researchers looked at whether individuals sought for cancer related information within a week of their interview and compared that with the news coverage on cancer the week before the participants' interview. Logistic regression model of analysis was used in determining relationships. The researchers gathered from this study that routine cancer news coverage is marginally significantly associated with cancer information seeking (Niederdeppe et al., 2008). The researchers concluded that the coverage of cancer news

is strongly associated with the search for cancer related information in individuals who have interest in health information presented in the news. Likewise, individuals who have a family member with a diagnosis of cancer were more likely to search for cancer related information after a news coverage on cancer than their counterparts who have no family history of cancer. In individuals with personal cancer history, there was no significant relationship between the search for cancer information and cancer related news. These individuals searched for cancer related information irrespective of news coverage. This study indicated the increased propensity to search for health information when there is a chronic disease or illness (Niederdeppe et al., 2008).

Management of Chronic Diseases

With the advent of the internet and the availability of health information has come the growing need for individuals to manage their chronic illness. Chronic illnesses/diseases are pathologic or physiologic alterations in health that persists for periods greater than three months (Lemone, Burke, Bauldoff & Gubrud, 2015). It is an alteration in health that cannot be healed or cured using medications or any form of therapy (Baumgartner, 2011). Due to the longevity of chronic illnesses, management is required for a long period of time to prevent/reduce exacerbations, deteriorations and early mortality related to the illness. Chronic diseases could be communicable; human papilloma virus infection, tuberculosis, human immunodeficiency virus causing acquired immunodeficiency syndrome (AIDS) or non-communicable; asthma, arthritis, osteoporosis, diabetes, glaucoma, cataract, hypertension, heart failure, and so on (Lemone et al., 2015).

Chronic disease, according to the Centers for Disease Control and Prevention (CDC, 2017) is the leading cause of death and disability in the United States. Data from the CDC

showed that seven of the top 10 causes of death in 2014 were chronic diseases. Heart disease and cancer together accounted for nearly 46% of all deaths related to chronic diseases (CDC, 2017). Due to the burden of chronic diseases, the United States spends more on chronic diseases than on any other illnesses or diseases; 75% of total health care resources are spent on chronic diseases (Zubialde, Mold & Eubank, 2009)

Chronic disease is a burden to the individual, the family, the community in which the individual lives, and the nation at large (CDC, 2017; Gupta, 2016). Individuals with chronic diseases experience various challenges that range from ineffective symptom management to coping with the psychosocial effects of the chronic illness (Rager, 2006). The ability to effectively cope with the burden of a chronic disease depends to a large extent on the understanding of the disease process and its management. Individuals, in their quest to understand what is happening to their bodies turn not only to the health care system, but also to the internet to understand symptoms, treatment options and strategies (Fox & Duggan, 2013; Rager, 2003, 2006). The process through which individuals try to make sense of their diagnosis and the various technical terms they are bombarded with from various informational resources is known as self-directed learning (Knowles, 1975). Self-directed learning is therefore a crucial element for survival in a crisis situation, as in the diagnosis of a chronic disease (Knowles, 1975; Rager, 2003).

Self-Directed Learning

Learning is a lifelong psychological process that takes place throughout the lifespan of an individual (Hammond, 2002; Jackson, 2006). It could be formal, non-formal or informal, intentional or unintentional, ranging from an organized classroom/environment to an unorganized/non-existent classroom where learning is passive (Jackson, 2006). Self-directed

learning in a crisis situation is informal with the intention of gaining understanding about disease diagnosis, treatment options and care for best outcomes (Jackson, 2006).

Self-directed learning according to Baumgartner (2011) is central to coping with chronic illness. According to Knowles, it is the best way to learn (1975). This method of learning equips individuals with the skills to learn independently without the help of a teacher, or a parent. It is "a process in which individuals take the initiative, with or without the help of others, in diagnosing their learning needs, formulating learning goals, identifying human and material resources for learning, choosing and implementing appropriate learning strategies, and evaluating learning outcomes" (Knowles, 1975, p. 18). This learning method is influenced by prior experiences and is based on the assumptions that learners are intrinsically motivated to learn out of curiosity and they search for resources to equip them with the essential skills needed to overcome identified problems (Knowles, 1975). Individuals with one chronic illness or the other are, therefore, proactive in their learning as they seek for information relevant to their well-being and existence (Knowles, 1975). They engage in self-directed learning to make sense of their medical diagnoses, signs and symptoms and how to manage their disease. They learn to adapt to the disease state, set new goals for themselves and re-evaluate what is important in their lives. This is with the hope and goal of restoring health, preventing future occurrences of disease exacerbations or other diseases, managing their diseases, and improving their quality of life (Zubialde, Mold & Eubank, 2009).

Self-directed learning, as much as it is a process, is influenced by the characteristics of the individual. Personal characteristics influence how the process of learning is conducted, the type of information sourced, the interpretation of the information received, and how the information is retained and applied. Newly diagnosed individuals are more likely to be anxious

and aggressive in their learning as they try to understand their body, the diagnosis and how to care for themselves (Baumgartner, 2006). A study conducted by Francabandera (1992) on patients with multiple sclerosis and their family members indicated that patients with less than 5 years diagnosis tend to desire to understand the disease process and how to live with it. On the other hand, individuals with greater than 5 years' diagnosis desire to know how the disease can be stopped. Family members of patients were also involved in learning about the disease their loved ones had to live with (Francabandera, 1992).

Jackson (2006) conducted a study on individuals living with primary immunodeficiency (PID) to understand how they engage with learning and how this, if at all, influenced the management of their illness. The study revealed that the participants engaged in self-directed learning to understand their diagnosis, manage their disease, and exercise control over their care. Likewise, Rager (2003) studied 13 women diagnosed with breast cancer and 12 men diagnosed with prostate cancer (Rager, 2006). It was found in the two studies that self-directed learning was a major factor in helping both the men and women cope with cancer diagnosis. Seeking out information about their diagnosis and treatment options were key factors in dealing with their crisis, especially when the information received from care providers was confusing (Rager, 2006). There were however differences in how the two groups learned. The men with prostate cancer were more likely to evaluate the available resources and information about the disease than the women with breast cancer. For the women, emotions related to breast cancer diagnosis were barriers to their understanding and interpretations of information related to the disease (Rager, 2006). The results of the study aligned with what Butcher and Sumner (2011) described in their article as the sense making paradox, where individuals often do not have the skills to evaluate and integrate new knowledge from new information into prior knowledge.

Chronic diseases are more common in individuals who are 65 years or older (Healthy People.gov, 2020). Approximately 60% of this group have been diagnosed with two or more chronic diseases. It was observed that about 14.5% of the US population was aged 65 or older in a 2014 study. This number is expected to be 9% higher by 2060 (Healthy People.gov, 2020).

Glaucoma

With increasing age, there is an increased risk for chronic eye diseases like glaucoma, cataract, macular degeneration, diabetic retinopathy, amblyopia and strabismus (CDC. n.d.). Glaucoma is defined as "a group of optic neuropathies associated with characteristic structural changes at the optic nerve head that may lead to visual field loss and ultimately, blindness" (Gupta & Chen, 2016, p. 668). The disease is classified as open angle, closed angle, or congenital glaucoma. Congenital glaucoma sets in during childhood and is less common than the other forms of the disease (NEI, 2020). Depending on the underlying condition, glaucoma can be classified as primary or secondary; secondary, if it is a result of trauma or other diseases and primary, if there is no history of trauma or other diseases (National Eye Institute (NEI), 2020; Senjam, 2020).

Glaucoma is the most common cause of irreversible blindness in the world. The disease is estimated to affect about 70-80 million people worldwide with 10-11% bilaterally blind at the time of diagnosis (Senjam, 2020; Weinreb et al., 2014). The disease is often asymptomatic in the early stages and its progression uneventful until late in the disease when vision loss has occurred (Gupta, 2016; Senjam, 2020). Treating this eye disease is somehow challenging for health care providers as there is currently no known cure. Effective management involves decreasing the intra ocular pressure of the diseased eye, which reduces the progression of the disease and prevent further damage to the eye. The diminished/loss of vision that results from this disease

leads to a reduction in the quality of lives of the affected patient (Park et al., 2015). The disease, though common in adults older than 60 years, can set in at any age. Glaucoma occurs in all populations but is more prevalent in people of African and Asian descents (Gupta, 2016).

Individuals diagnosed with glaucoma and other chronic diseases do not get adequate information about the disease from their healthcare providers or the information provided is confusing. They resort to seeking information about the disease from other sources. Other sources most frequently sought include the internet, social media, books, family, and friends. Unlike the extensive studies available for cancer, there is paucity of information about where individuals seek for information about glaucoma. It is also unclear what factors will motivate individuals to search for glaucoma related information. However, Lyons, Ellard, McElnea and Townley (2017) evaluated how the diagnosis of a celebrity with glaucoma impacted the information seeking behavior about glaucoma. The researchers concluded in the study that the search for glaucoma information went up a five-fold after a celebrity declared publicly that he had glaucoma.

Google Search Engine

In addition to the different characteristics that predispose individuals to search for health information online, researchers also carried out studies to determine the type of information searched by health information seekers. These results have been used to determine disease prevalence and outbreaks or pending outbreaks (Dehkordy et al., 2014; Harsha, Schmitt & Stavropoulos, 2014). Several studies were conducted using Google Trends to investigate what people search for about various diseases and chronic conditions (Dehkordy et al., 2014; Harsha, et al., 2014; Hassid, Dreher, Tong, Ghiraldi & Friedlander, 2018).

Google Trends is a tool that shows the changes in the flow of information searches by people all over the world (Google, 2018). It is therefore a good tool to determine the volume of information searched by individuals in the United States and around the world. An example was a study conducted by Brigo and Trinka (2015), where the investigators studied the online information seeking behavior for status epilepticus (SE) over a period of ten years, from 2004 to 2014. The results of the investigation showed that most of the people who used the Google search engine to search for SE, searched for information relating to the definition of SE, its subtypes and management. Hanna and Hanna (2018) conducted another study in the United Kingdom using Google Trends to determine what people searched for on the internet in relation to some antibiotics. The study indicated that individuals searched for information relating to "specific infections (i.e. urinary tract infection, chest, skin, throat, chlamydia, malaria and toothache), the side effects of the medications, concomitant consumption of alcohol, administration and dosage, what an antibiotic is and how it works" (Hanna & Hanna, 2018, p. 3). Furthermore, these researchers determined the sites individuals are directed when searching for medications or health conditions. The authors found that the websites individuals are directed to when searching for prescription medications differed from those to which they are directed when searching for over-the-counter medications. In addition, the sites people are directed to for non-self-treatable conditions are different from those for self-treatable conditions (Hanna & Hanna, 2018). Other studies involving the use of Google Trends attempted to predict an association between online searches and the prevalence or occurrence of disease conditions.

Furthermore, Hassid et al. (2017) examined if there was a relationship between the search for gastrointestinal symptoms on the internet and inpatient/outpatient treatment. The researchers used the Google search engine to determine trends from 2004 to 2014. The researchers correlated

the results of the search with inpatient and outpatient databases. The databases employed by the researchers were the National Inpatient Sample (NIS) database and the National Hospital Ambulatory Medical Care Survey (NHAMCS). The NIS database is a "database of inpatient discharge abstracts collected via federal-state partners as part of the Agency for Healthcare Research and Quality's Healthcare Cost and Utilization Project" (Hassid et al., 2017, p. 589). The NHAMCS "assesses services offered at hospital outpatient departments and provides de-identified outpatient visit data. NHAMCS uses probability sampling procedures allowing the generation of nationally representative estimates" (Hassid et al., 2017, p. 589). The correlation between Google Trends data and NIS output was calculated using the Pearson correlation coefficient, likewise the results from Google Trends was correlated with NHAMCS output. The results of the study showed that the frequency of the searches on Google for the three GI symptoms (diarrhea, vomiting and dysphagia) had high correlations with the frequency of inpatient cases treated as obtained from the inpatient data. The researchers did not obtain a correlation between the search trends and the outpatient data.

With the review of these studies, it is evident that individuals search for health-related information on the internet to help them in managing their disease symptoms when they are unable to reach health care professionals. It may also help them to understand the information they receive from health care providers. The various characteristics that predispose individuals to search for online health information regarding various disease conditions has been widely studied. It is, however, not clear if the same variables will predict the search for information on glaucoma. In addition, the search for online information about diseases has proved useful in tracking diseases and their prevalence in different regions. The ability to track the information accessed by individuals without revealing their identities is possible through Google Trends. If

people search for information online about glaucoma using Google, to track such information will reveal the information consumers want to know about glaucoma and the type of information retrieved. A knowledge of this will help health care professionals and government agencies to provide appropriately targeted and accurate information to individuals at the right time and at the right level for the understanding of the consumers.

Consumers are sometimes unable to evaluate health information websites and the available health information on diseases due to their level of health literacy. Information available about glaucoma online can be evaluated for its readability and accuracy using available tools and comparison made with the information available on the National Eye Institute (NEI) website, a gold standard government agency website.

Addressing Gaps in Literature

The review of the literature in this chapter reveals the literacy of individuals is associated with their health literacy. However, the level of educational attainment does not correspond to health literacy or electronic health literacy. The health literacy of an individual determines how well the individual is able to search for health information, understand the information and use it in making informed decisions about health. Individuals search for health-related information online. The information searched by individuals about glaucoma is not known, neither is the type of information available to searchers during their search. This study sought to evaluate the type and trend of online information search about glaucoma via the most frequently used internet search engine, Google. The value of the information obtained from the google search engine as an educational tool for individuals who want to learn about glaucoma was explored. Finally, since health literacy may predict the ability to effectively use online information, this study

proposed to evaluate the ehealth literacy of African immigrants living in Missouri and determine how it may affect their knowledge and online information seeking behavior about glaucoma.

CHAPTER 3

METHODS

Health Literacy

This chapter presents a detailed description of the research methods used in this study and will be outlined in five sections: research design, population and sample selection, instrumentation, method of data collection, and plan of analysis for the study.

Purpose of the Study

It has been estimated that the prevalence of glaucoma in African Americans ranges from 4% in people aged 50 – 59 to 13% in those aged 80 – 89 years old. These rates are consistently higher than the 2% - 3% prevalence rate reported among equivalent age groups in the general population of the United States (Tielsch, Sommer, Katz, Royall, Quigley & Javitt, 1991). It has therefore been suggested that individuals of African ancestry may carry a genetic predisposition to glaucoma (Racette, Wilson, Zangwill, Weinreb, & Sample, 2003). The past decade has seen a dramatic increase in the number of African immigrants to the United States; they now constitute about 5% of the US population (Anderson, 2017, Omenka, Watson & Hendrie, 2020;). A study in Minnesota, where African immigrants now constitute approximately 2% of the state's population have suggested that this group may face impediments that include language barrier and difficulty in navigating the healthcare system (Cernasev et al., 2020), suggesting low health literacy among African immigrants compared to the general population of the United States. The health literacy of African immigrants in the United States has not been extensively studied, neither has their use of the internet as a source of health information previously explored. Thus, the purpose of this study was to evaluate the health literacy of African immigrants living in the

state of Missouri, evaluate their use of the internet and social media as information source, and determine the factors that may predict their knowledge of glaucoma. Additionally, this study will determine the trend of online information search about glaucoma over a period of 10 years from 2006-2016, identify the triggers of observed surges in glaucoma information search, and evaluate the quality of the information available to online information seekers during each surge in the search for glaucoma information.

Research Questions

To achieve the stated goals of the study, the following specific research questions were used:

1. What type of glaucoma information do individuals search on the internet using the google search engine?
2. What is the trend of online search for glaucoma information using google over the 10-year period from 2006-2016?
3. What are the triggers for an increase in online search for glaucoma when spikes in searches were observed from 2006-2016?
4. What is the health educational value of the information materials available during a surge in online google search for glaucoma over the period studied from 2006 to 2016?
5. What are the factors that predict the ehealth literacy of African immigrants in the state of Missouri?
6. Does ehealth literacy predict the knowledge of African immigrants about glaucoma?
7. What factors will predict knowledge about glaucoma in African immigrants in the state of Missouri?

The first four questions were based on the general population in the United States of America (USA) and their search for information on the internet, with particular focus on

glaucoma. The last three questions were answered using a sample of African immigrant population living in the state of Missouri.

Sample

The population of interest were African immigrants in the US. A convenience sample of this population was selected from churches where African immigrants were the majority congregants in three cities in Missouri, a state in the Midwestern region of the US. A pastor in one of the churches was a link to the other churches from which participants were recruited. The individuals who chose to participate and were available on the day of data collection were the samples used in this study. Sample selection criteria included men and women aged 18 years and above, English speaking, and were African immigrants or children of African immigrants (first generation).

The proposal for this study was submitted and received approval from the Institutional Review Board (see Appendix A). Data collection was conducted from October 2019 to January, 2020. Participants were recruited from churches in three cities in Missouri (St Louis, Columbia, and Kansas City) after a recruitment script was read to them. The script was a brief summary of the purpose of the study, including possible risks and benefits associated with participation. The participants were assured of the anonymity, privacy and confidentiality of their responses. There were no incentives offered for participation in the study. Participants gave consent to participate by reading and signing the consent forms. Survey questions were distributed to those willing to participate after church services. The signing of informed consent and completion of survey questions required about 10 to 15 minutes. The final sample was made up of 265 African immigrants recruited from Missouri State, in the US.

Instrumentation

This work used the Google Trend database. This database was chosen because Google search engine is currently the most refined and widely used search engine of all the available search engines (Curtois, Slechten & Coenen, 2018, Netmarketshare, 2018, Precision Inc., 2006). The search engine accounts for over 200 million searches per day (Precision Inc, 2006). Also, it is not easily susceptible to manipulations and junks. This has encouraged its use in the search of online information relative to other search engines like Yahoo and Bing. Baker (2011) in his comparison of the top three search engines concluded that of all the searches made on the internet, about 65.09% of those searches were made using the Google search engine. The remaining 35% was shared between Yahoo (15.89%), Bing (13.10%) and the other search engines (5.92%). In addition, the Google Trend database was started in 2004 to simplify research work aimed at tracking year-to-year changes in online searches.

Furthermore, several studies in the emerging field of "infodemiology" have consistently used this tool to monitor the prevalence and distribution of diseases worldwide; the findings of such studies showed a strong correlation with traditional epidemiological methods (Mavragani, 2020).

Google Trends data were therefore assessed in this study using Google Trends. Google Trends is an online database, which compiles the results of every internet search done since 2004 using the Google search engine (Google Trends, n.d). The results of a search using a given term are expressed as relative search volume (RSV). This scaled value expresses the volume of search during the week, month or year of interest relative to the search volume during the week, month or year that has the highest number of searches for that term. The week with the highest search volume is assigned an RSV of 100 while the other weeks have values that range from 0 to 99. A

plot made using this value can be overlaid with specific news events to determine possible trigger events for changes in trend. Google Trend data has emerged as an effective method to measure user behavior and predict events of public health importance e.g. influenza outbreaks (Google, 2018; Hassid, et al. 2017).

Google Trends presents data on a queried term based on the number of times the term has been searched using google engine compared to other terms. The result of the search is scaled on a 0-100 range to determine its proportion compared to all other terms searched at the same time. Google trend reveals the status of a search term relative to other search terms in the same time period. The presented search result is a relative frequency of the search term obtained by dividing the search term by the total number of internet searches. Google Trends analyzes data for popular terms so that, for a given time period, search terms with low volumes are awarded a zero. In addition, repeated searches from the same user are eliminated, if done over a short period of time. This way, it is possible to estimate which terms are most searched over a time period (Google, 2020; Google News Initiative, 2019).

eHealth Literacy Scale

The ehealth literacy of participants was assessed using the ehealth literacy scale, developed by Norman and Skinner in 2006, to measure consumers' perceived skills at locating, appraising and applying electronically available health information to solving health problems (Norman & Skinner, 2006). It is an eight-item scale that combines individuals' health literacy skills with their ability to use the computer. The tool is reliable and easy to administer (van der Vaart, Deursen et al., 2011). It has been used in several studies (Brown & Dickson, 2010; James, 2016; Norman & Skinner, 2006; Robinson & Graham, 2010). It uses a 5-point Likert scale to

answer questions with response options ranging from “strongly agree” to “strongly disagree”. It has consistently captured the health literacy concept in different studies.

An item analysis of the tool when used on 664 individuals (13-21 years of age) at four-point intervals over a period of 6 months yielded a Cronbach’s alpha, α of .88 (Norman & Skinner, 2006). Item-scale correlations between items in the study, ranged from r = .51 to .76. Test-retest reliability was modest over the 6-month period of the study (r= .68 to .40). Another study conducted by van der Vaart et al. (2011) to evaluate the reliability of the tool concluded that the internal consistency of the scale was high and reliability adequate. The Cronbach’s alphas obtained from the two populations studied was .93 and .92. In the current study, a Cronbach’s alpha of .93 was obtained. Item-total correlation ranged from r = .67 to .81. Mean inter-item correlations r = .619 (range; r = .38 to .85). Mean score was 30.94 (Standard Deviation = $\pm$6.50).

Eye-Q Test

The knowledge of glaucoma was assessed using the eye-Q test, a 10-item instrument consisting of true, false or not sure survey questions. The test was developed by the National Eye Health Education Program (NEHEP) and is publicly available. The Cronbach’s coefficient for this test was moderate at 0.592 (Rao et al., 2016). The NEHEP knowledge assessment was previously given high ranking by glaucoma clinicians as most useful for clinical practice. Rao et al. (2016) however, suggested from their study that it lacks internal consistency but that it has a reasonable level of difficulty. In this study, the Cronbach’s alpha was .78, item-total correlation ranged from r = .163-.600. Mean score was 4.07 and standard deviation was 2.66 (see Appendix B for survey questions).

Data Collection Procedures

Google Trends Data

In this study, Google Trends was used to access data on glaucoma information search for a period of 10 years (2006-2016). The search term "glaucoma" was the keyword used to query Google Trends to obtain the relative search volume related to glaucoma over the ten-year period. The search data was limited to internet users searching for information within the United States of America. To identify the trigger events for glaucoma information searches, focus was placed on months when spikes in searches were observed. A Google news search, limited by time, was then done to identify the specific news items during this period that relates to glaucoma.

Determining the Readability Level of Information on Websites

Search Strategy

The months with spikes from Google Trends when the average volume of glaucoma search was greater than 85 (>85) were investigated to determine the news events that could have influenced individuals to search for information on glaucoma (see result in Table 4). After this, Google search engine was queried to determine the information received by individuals when they searched for information about glaucoma at this specific time (time-limited web search). The query was conducted on August 29, 2020. The search was conducted in the "incognito mode" to prevent the influence of previous browsing activities. The tool section of google chrome was used to change the date of search to the months when there were spikes in glaucoma search. The first page of the web results retrieved were assessed for eligibility in this study. Websites with duplicates, videos, broken link, medical or scientific journals were excluded. In addition, webpages intended for healthcare professionals were excluded. The remaining websites

were evaluated for the readability of the information provided using freely available readability indices.

Inclusion criteria:

Websites containing patient education materials on glaucoma

Websites written in English

Exclusion Criteria:

Information targeted at healthcare professionals

YouTube videos

Medical or scientific journals

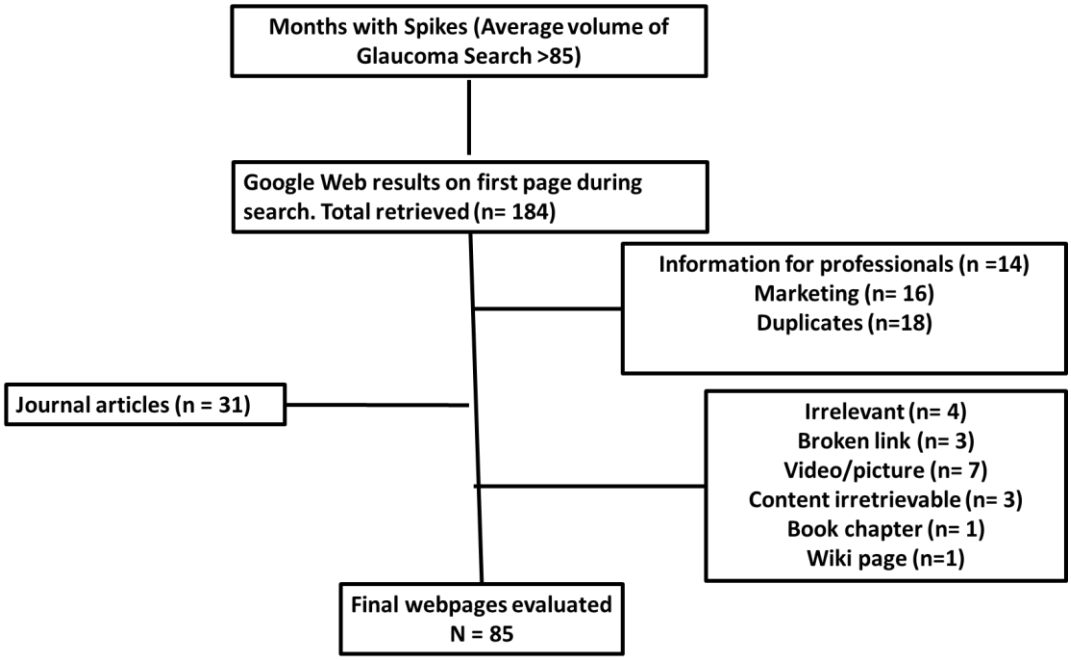
Advertisements

Book chapters

The difference between patient education and marketing was made by screening websites for content. If a site is focused on promoting an optometrist/ophthalmologist or a group of ophthalmologists, group practices, or a medication or treatment procedure, instead of providing information on glaucoma, treatment options/procedures, the website was excluded.

Figure 3

Flow diagram of websites included in the analysis



Data Processing

Glaucoma related information available on each website was copied to a separate Microsoft Word document. When a website contained glaucoma information that exceeded a page, additional pages were included up to 1000 words. The text retrieved were processed for readability by deleting double spaces and entangled images.

The readability test tool, a free online readability assessment program (WebFX, 2020) was used to assess the readability level of websites in this study. The retrieved text from each webpage was copied and pasted in the "test by direct input" section of the tool. The tool calculated the overall average reading grade level of text inputted into it and the readability indices. The tool also calculated the text statistic of the text inputted. The text statistics are presented as "number of sentences, number of words, number of complex words, percent of

complex words, average number of words per sentence, and average number of syllables per word" (WebFX, 2020). The tool in calculating the indices, uses the number of sentences, words, syllables, and characters in the text put into it. The readability indices calculated are as follows:

The Flesch Reading Ease Score.

Used to evaluate the difficulty of a text. Proposed by Rudolph Flesch to determine the grade-level of the reader of a text.

The formula = 206.835 – (1.015 x ASL) – (84.6 x ASW).

ASL = total number of words in text divided by total number sentences.

ASW = average number of syllables per word (number of syllables) divided by number of words. The Flesch Reading Ease score ranges from 0 to 100.

Interpretation: A low Flesch Reading Ease score corresponds to a difficult to read text while a high number correlates to an easy to read text; a score of 90-100 corresponds to a very easy to read text and 0-29 a very confusing text (Readability Formulas, 2020, WebFX.com, 2020).

Flesch–Kincaid Grade Level.

This estimates the grade level the readers of a text would have to be able to understand a given text. Formula: (0.39 x ASL) + (11.8 x ASW) – 15.59 (Readability Formulas, 2020, WebFX.com, 2020).

Gunning FOG Index (GFI).

This predicts the years of formal education needed to understand a text. Calculating this index involves counting the number of exact words and syllables. The index is based on the average sentence length (ASL) and the percent hard word (PHW).

PHW = number of words with three or more syllables that are not proper nouns divided by total number of words in the text (Readability Formulas, 2020, WebFX.com, 2020).

GFI = 0.4 (ASL + PHW)

Simple Measure of Gobbledygook (SMOG) Index.

Gives the years of education needed to comprehend a text. Calculating this index depends on the whole passage. It involves counting words with three or more syllables in the first 10 sentences, 10 sentences in the middle and 10 at the end of the text and adding them together.

SMOG index = 3 + square root of polysyllable count (Readability Formulas, 2020, WebFX.com, 2020).

Coleman–Liau Index.

This was developed by Meri Coleman and T. L. Liau to evaluate the grade level needed to understand text in the US (Coleman & Liau, 1975).

The index uses letters per word instead of syllables in a word or sentence length. A score on this index indicates the level of education in the US a person needs to understand the text.

The index formula = .0588 x (average number of characters or letters/100 words) - 0.296 x (average number of sentences/ 100 words) – 15.8. A text score of 8.5, means that the text can easily be understood by a student in the 8^{th} or 9^{th} grade.

Automated Readability Index (ARI).

This is a readability test that ascertains the extent to which a text can be understood. This index estimates the grade level required to understand a given text. It is based on word difficulty

(number of letters in each word) and sentence difficulty (number of words in every sentence). The formula is given by:

$$ARI = 4.71 \times (\text{letters /word}) + 0.5 \times (\text{words/sentence}) - 21.43$$

An ARI score of 10 means the text should be understood by grade 10 high school students who are 15-16 years old (Readability Formulas, 2020, WebFX.com, 2020).

Sampling from a population

Participants were recruited from churches with African immigrants as the predominant congregants. Samples were collected in three major cities in Missouri: Columbia, St Louis, and Kansas City. The researcher was allowed by the pastors in the churches to address and inform their congregation about the study- recruitment script read to the congregation (See Appendix A). Each participant was given an information letter that outlined the purpose, benefits and possible risks associated with participating in the study. In addition, information about the researcher, the advisor, and the Institutional Review Board were provided. The researcher, with the help of church ushers distributed the questionnaires after church services to those willing to participate. During the information session, the participants were notified of the need for a follow-up on the eye-Q test. At the end of the first visit, The National Eye Institute (NEI) information about glaucoma was sent to the pastors of the churches to post on the churches' WhatsApp page (easily accessible, free software for sending messages, making voice and video calls, and for sharing documents and images). The eye-Q test was re-administered to the participants two weeks after the first test. The response rate of the follow-up test was less than the initial administration of the survey. Only 120 of the 265 participants completed the follow-up survey.

Plan of Data Analysis

SPSS statistical software version 26.0 was used to analyze collected and online data. Examining the research questions:

Table 1

Research questions and methods used for data analysis

RQ1: What type of glaucoma information do individuals search on the internet using the google search engine?	Search Google Trends and identify specific phrases that Google users searched during the period of study. List the most common searches.
RQ2: What is the trend of online glaucoma information search from 2006 to 2016?	Determine the volume of search for information on glaucoma using Google Trends. Draw a graph of relative search volume over time.
RQ3: What are the triggers for an increase in online search for glaucoma when spikes in searches were observed from 2006-2016?	Google search
RQ4: What is the health educational value of information materials available during a surge in online google search for glaucoma over the period studied from 2006 to 2016?	Readability scale
RQ5: What are the factors that predict the ehealth literacy of African immigrants in the state of Missouri?	Descriptive statistics, Binomial test, Independent t-test Multiple regression Repeated measures
RQ6: Does ehealth literacy level among African immigrants to the United States predict their knowledge about glaucoma?	Linear regression
RQ7: What factors will predict knowledge about glaucoma in African immigrants in the state of Missouri?	Multiple regression

As discussed in Chapter 2, factors that will predict health literacy include demographic variables and factors such as access to a computer. Demographic factors were evaluated in this study. The

eHEALS, an 8-item measure of ehealth literacy measures individual's ability to find, evaluate and apply health information obtained electronically to solve health problems. The eHEALS was administered to the study population to assess their skills and abilities to effectively obtain and use electronically available health information.

Multiple regression analysis was carried out to examine the relationships between the various independent variables in the study with the dependent variables. Multiple regression could be standard or hierarchical. Standard multiple regression involves the prediction of the dependent variables from two or more independent variables. This analysis was appropriate for two of the research questions; 5 and 6. Linear regression was used to determine if ehealth literacy level among African immigrants to the United States can predict their knowledge about glaucoma. For the multiple regression, a stepwise backward selection approach to analysis was employed to determine the specific independent variables that predict the dependent variables under study.

A binomial test was conducted to compare the individual characteristics of the sample population with the general population or what is obtained in another study. An independent t-test was conducted to determine differences in sample means between the different groups represented in the sample; specifically, groups based on age, income, education, gender, employment, and access to a computer.

Multiple Regression Analysis

A multiple regression analysis that included all the variables related to the research question were included in the regression analysis to predict the ehealth literacy of participants. Most of the independent variables were categorical variables that needed to be recoded before their use in regression analysis. Dummy coding of variables not exceeding four levels and

criterion coding of categorical variables exceeding four levels were employed. The variable "age" consists of more than four levels but was dummy coded. The criterion coding involves the coding of category levels using the mean of the dependent variable. In the dummy coding, the categories were coded 0 to 1. Individuals received a code of "1" or "0" depending on if they belong to a category or not.

For research questions 4 and 6, the regression model was constructed using the backward elimination stepwise regression approach. This approach involves starting with all the predictor variables in the research question and deleting the variables one at a time until further deletion would lead to a significant loss in R square.

For ehealth literacy, the regression model was constructed using the backward elimination approach. The final model was arrived at, after 26 steps of elimination. The r square changed from .349 in the initial model to .313 in the last model. The procedure started with 35 independent variables (IVs) and ended with 10 variables. The F statistic decreased from 2.822 to 2.422. The loss of independent variables from one step to the other was not significant. The resulting model had three variables that had zero included in the interval for the slope. All the variables were left in the model to predict the score on the ehealth literacy scale and consequently ehealth literacy.

Regression model for the prediction of score on the ehealth literacy scale, which predicts ehealth literacy, is given by the simple regression equation:

$$Y' = \alpha + b_1X_1 + b_2X_2 + b_3X_3 \ldots\ldots + b_kX_k + e \quad (1)$$

Where:

α is the intercept or constant

Y' = score on ehealth literacy scale

b or β = the regression coefficient

X = the observed score

For research question 5, to determine if ehealth literacy can predict the knowledge of African immigrants about glaucoma, a simple regression analysis was used to determine if ehealth literacy can predict an individual's score on the eye-Q test.

The simple regression equation $Y' = \alpha + bX + \ldots\ldots e$ -(1)

α is the intercept or constant.

Summary

This chapter gives an overview of the different tools used in data collection and the data that will be analyzed in this study. The research questions employed the use of different statistical methods in the analysis of data. The sample size used in this study was 265, providing an adequate sample size for the study.

Chapter 4

RESULTS

This chapter presents the results of this quantitative study. The analyses of the data collected in this study are used to provide responses to the research questions started with at the beginning of the study.

Purpose of the Study

It has been estimated that the prevalence of glaucoma in African Americans ranges from 4% in people aged 50 – 59 to 13% in those aged 80 – 89 years old. These rates are consistently higher than the 2% - 3% prevalence rate reported among equivalent age groups in the general population of the United States (Tielsch, Sommer, Katz, Royall, Quigley & Javitt, 1991). It has therefore been suggested that individuals of African ancestry may carry a genetic predisposition to glaucoma (Racette, Wilson, Zangwill, Weinreb, & Sample, 2003). The past decade has seen a dramatic increase in the number of African immigrants to the United States; they now constitute about 5% of the US population (Anderson, 2017, Omenka, Watson & Hendrie, 2020;). A study in Minnesota, where African immigrants now constitute approximately 2% of the state's population have suggested that this group may face impediments that include language barrier and difficulty in navigating the healthcare system (Cernasev et al., 2020), suggesting a low health literacy among African immigrants compared to the general population of the United States. The health literacy of African immigrants in the United States has not been extensively studied, neither has their use of the internet as a source of health information previously explored. Thus, the purpose of this study was to evaluate the health literacy of African immigrants living in the state of Missouri, evaluate their use of the internet and social media as

information source, and determine the factors that may predict their knowledge of glaucoma. Additionally, this study will determine the trend of online information search about glaucoma over a period of 10 years from 2006-2016, identify the triggers of observed surges in glaucoma information search, and evaluate the quality of the information available to online information seekers during each surge in the search for glaucoma information.

Research Questions

To achieve the stated goals of the study, the following specific research questions were used:

1. What type of glaucoma information do individuals search on the internet using the google search engine?
2. What is the trend of online search for glaucoma information using google over the 10-year period from 2006-2016?
3. What are the triggers for an increase in online search for glaucoma when spikes in searches were observed from 2006-2016?
4. What is the health educational value of the information materials available during a surge in online google search for glaucoma over the period studied from 2006 to 2016?
5. What are the factors that predict the ehealth literacy of African immigrants in the state of Missouri?
6. Does ehealth literacy predict the knowledge of African immigrants about glaucoma?
7. What factors will predict knowledge about glaucoma in African immigrants in the state of Missouri?

This study sought to address the seven research questions listed above. The results of the study in response to the research questions are hereby presented.

RQ1: What type of glaucoma information do individuals search on the internet using the google search engine?

The type of online glaucoma information searched by individuals in the United States using the Google search engine over a 10-year period from 2006 to 2016 are presented.

Google trends provided information about the first 25 keyword searches used by individuals all over the US to search for information relating to glaucoma during the time-period investigated (2006-2016). Table 2 shows queries typed into Google search engine by individuals searching for information on glaucoma. The table reveals the top terms associated with the search term "glaucoma". These are terms that were most frequently searched in the United States during the search period 2006-2016. As seen in this table, it is apparent that searchers were interested in understanding glaucoma as a disease of the eye: "eye glaucoma". There was also a strong interest in knowing the nature and symptoms of glaucoma: "what is glaucoma", "symptoms of glaucoma". In general, there are two types of glaucoma – closed angle glaucoma and open angle glaucoma. Searchers showed interest in understanding these two types of glaucoma by searching for "angle glaucoma" and "open angle glaucoma". Furthermore, searchers were interested in knowing the relationship between glaucoma and increased pressure in the eye: "glaucoma pressure". Finally, there was an increase in the search for how to manage glaucoma in individuals with this disease: "glaucoma treatment", "glaucoma surgery", "glaucoma drops", "glaucoma marijuana". The numbers represent the volume of search relative to the most searched word or phrase: for example, 100 for "eye glaucoma" and 14 for "glaucoma cause" means "glaucoma cause" is searched only 14 times as frequently as "eye glaucoma".

Table 2

Top glaucoma-related terms searched in the United States (US) from 2006 to 2016

TOP Searches (What was at the top overall)	Volume
eye glaucoma	100
glaucoma symptoms	52
angle glaucoma	44
what is glaucoma?	40
glaucoma treatment	30
glaucoma surgery	28
glaucoma pressure	26
glaucoma drops	20
glaucoma vision	19
glaucoma causes	18
symptoms of glaucoma	16
open angle glaucoma	15
glaucoma eye drops	15
glaucoma marijuana	15
glaucoma cause	14
glaucoma test	14

Table 3 shows the rising terms associated with the search term “glaucoma”. These are terms related to glaucoma that had the most significant growth in volume from 2006 – 2016. It is the search volume compared to other search words in the time-period studied. Each rising search

term is a percentage of the term's growth compared to the previous time-period. The "breakout" obtained for the search terms indicate that the search terms grew by more than 5000% (Google Trend, 2018; Mavragani et al., 2019).

Table 3

Rising related search terms associated with glaucoma

RISING (What was increasing in popularity)	Volume
glaucoma icd 9	Breakout
fetty wap	Breakout
glaucoma icd 10	Breakout
fetty wap eye	Breakout
medication for glaucoma	Breakout
high eye pressure	Breakout
weed for glaucoma	Breakout
how to treat glaucoma	Breakout
is glaucoma hereditary	Breakout

RQ2: What is the trend of online search for glaucoma information using google over a period of 10 years from 2006-2016?

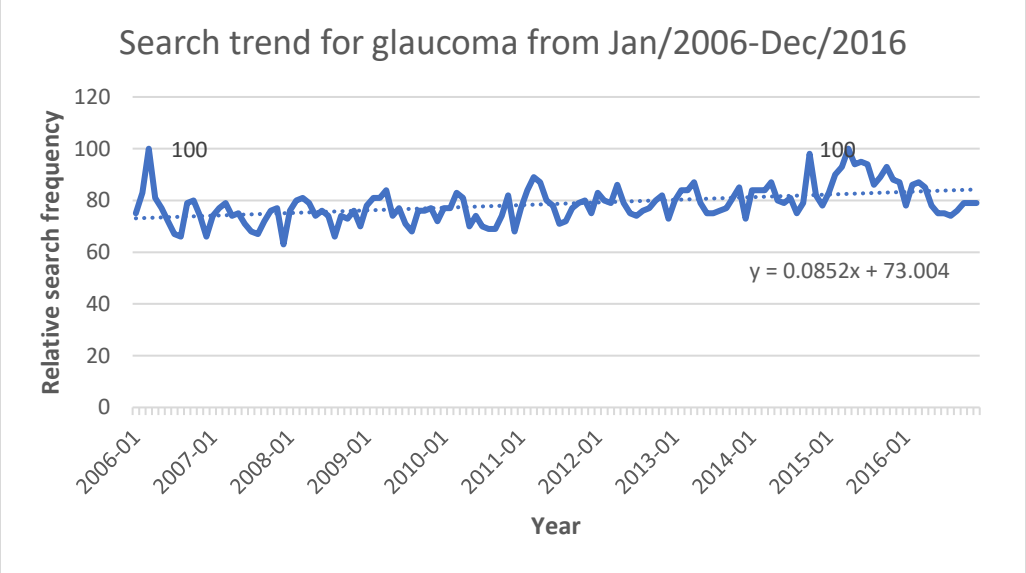
This presents the trend of search for glaucoma information in the US for a period of 10 years from 2006 to 2016 using the Google search engine.

Figure 4 shows the output of Google Trends search for the term "glaucoma" in the US from January 2006 to December 2016. The graph represents the search frequency for glaucoma over a period of 10 years. The relative search volume is relatively stable; it ranged from 64 to 100. This finding suggests that interest in glaucoma was stable over the 10-year-period.

However, a few periods of peak volume searches that suggested increased interest in glaucoma were noted. The first peak volume of search (100%) was obtained in March 2006; an increase in search for glaucoma was first noticed in February 2006 but peaked in March of that year. The second surge in searches for glaucoma occurred between March and April 2015, with a peak (100%) in April 2015. The search data show a rising trend over time from 2006 to 2016. In general, the relative search volume was above 85% from Feb 2015 to December 2015, making this the only year in the search period studied when the search volume trended higher than 85 for a period of 11 months. Thus, there was an unusually higher interest in glaucoma in 2015 when compared to other years. In general, the search volume for glaucoma on Google trended upwards from 2006 to 2016 (slope of the trendline = 0.0852), an indication of an increasing interest in this condition in the United States over the 10-year period examined.

Figure 4

Search volume for glaucoma from 01/01/2006 to 12/31/2016

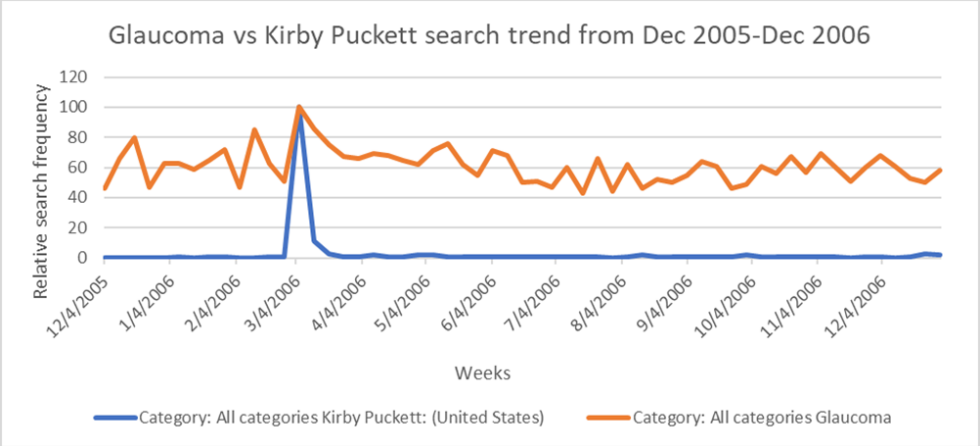


Peak searches were associated with specific events. For example, the peak volume obtained in March 2006 corresponds to World glaucoma awareness month and the news of the

death of Kirby Puckett. This well-known basketball player retired from the sport due to poor vision related to glaucoma. The relative volumes of Google searches for Kirby Puckett and searches for glaucoma before and after his death were compared using Pearson correlation. This test confirmed that the search for this athlete is directly correlated to the increase in search for glaucoma with (Pearson correlation coefficient $r = .57$, $p < .001$) (Figure 5). Using this statistical approach, peak search periods from 2006 to 2016 were positively correlated with specific events associated with well-known celebrities, new legislations and announcement of new drugs for the treatment of glaucoma (Research Question 3, Table 4).

Figure 5

Search Trend for glaucoma vs Kirby Puckett from Dec 1/2005 to Dec 31/2006



Similarly, the April 2015 peak was probably associated with the news of Roseanne Barr's gradual loss of sight to glaucoma. Roseanne Barr was an actress and a celebrity. More than one news media had the news (Los Angeles Times, 2015; The Herald, 2015; The Wrap, 2015). In addition, there was the news about Fetty Wap, an American rapper who lost vision in his left eye to congenital glaucoma (Music TV, 2015). There was also news about new surgical methods for

treating glaucoma and cataract (Miami Herald, 2015). Other peak periods with search volumes of relative frequencies above 85% are itemized in Table 4.

RQ3: What are the triggers for an increase in online search for glaucoma when spikes in searches were observed from 2006-2016?

The months associated with peaks or spikes on the graph in Figure 4 were investigated for news of events related to glaucoma in terms legislations, announcement of new treatment methods, and celebrities announcing their diagnoses or life with the disease.

Table 4

Periods of spikes in glaucoma search on Google Search Engine

Relative search Volume	Month/Year	Event
99	March/2006	• News: Kirby Puckett dies – he retired early due to glaucoma (CNN, 2006; ESPN, 2006). • Event: World glaucoma awareness week.
89	March/2011	• News: Woman's glaucoma medication catches fire (CNN, 2011). • News: City ophthalmologist carries out unnecessary procedure to treat glaucoma.
87	April/2011	• News: twin sisters, born blind, have eyes surgically restored (Roe, 2011).
87	April/2013	• Policy Change: A change in policy regarding the issuance of medical certificate to aviation applicants with glaucoma. • Policy Change: Florida passes law to give prescriptive powers to optometrists to order antiglaucoma agents.

		• News: Sixto Diaz Rodriguez (Sugar man) needed assistance to get on stage for his performance due to glaucoma related vision loss. • Policy Change: prescription marijuana to treat glaucoma and six other diseases.
98	Oct/2014	• News: Bono has glaucoma (CNN, 2014; The Guardian, 2014)
87	April/2014	• News: Whoopi Goldberg uses cannabis to treat her glaucoma
90	February/2015	• News: Innovations in the glaucoma treatment procedures (Clarke, 2015). • News: Fetty Wap, a rapper, diagnosed with congenital glaucoma very early in life (Lipshutz, 2015)
93	March/2015	• News: Aerie Pharma industries completed enrollment for phase 3 trial of their glaucoma medication. • Whoopi Goldberg advocates for the use of medical marijuana in treating glaucoma (Mohr, 2015). • Event: World glaucoma week, March 8-14 (Basu, 2015; Starbroek News, 2015). • News: NASA investigated visual impairments in astronauts as a result of space travels. (Nale, 2015).
100	April/2015	• News: Roseanne Barr, losing her vision to glaucoma (Benedietto, 2015; CNN, 2015; Dzurilla, 2015).

		• News: Fett Wap lost his eye to congenital glaucoma (Music Television, 2015; Starcasm, 2015). • News: new surgical method of treating glaucoma and cataract (Miami Herald, 2015)).
94	May/2015	• News: dogs have glaucoma too (Shapiro, 2015; Waxman, 2015). • New: increased risk of glaucoma in owners of cats compared to a decreased risk in owners of dogs (Knapton, 2015). • News: Edward Sheeran, a musician, had surgery as a toddler to prevent glaucoma (Gabraldi, 2015). • BBC news on the ban of toning creams in Ivory-Coast because of the risk of glaucoma associated with its use (BBC news, 2015).
95	June/2015	• News: Celebration of the professor who invented the first drainage device used in the treatment of glaucoma (Otago news, 2015). • News about the use of marijuana and the history of bills passed on it (Lane, 2015). • News: Promise of an increase in the available treatment options for glaucoma in 2016 (Healio News, 2015). • News: Possible exploitation by care providers related to fear of loss of vision to glaucoma and cataract (Consumer Report, 2015)
93	July/2015	• News: Bono raises money for vision initiatives (Exclaim, 2015; New Musical Express, 2015)

		• News: Glaucoma medication that can be used to treat Tuberculosis (Medical express, 2015).
86	August/2015	• News: Approval of a new treatment procedure for glaucoma (Newswire, 2015). • News: Legalization of marijuana in Georgia for the treatment of glaucoma and other diseases (Atlanta magazine, 2015). • News: Christopher Duncan who lost his eyes to glaucoma in 2012 contested against a recumbent republican candidate (Berman, 2015).
89	Sept/2015	• News: Allergan to acquire Aquesys, a glaucoma treatment company (Allergan, 2015; Healio, 2015). • Aerie Pharmaceuticals' new glaucoma drug failed at phase 3 trial (Fidler, 2015).
93	October/2015	• News: Democratic Agriculture commissioner candidate supports marijuana in treating glaucoma and other ailments (Gossum, 2015). • News: Stent developed for glaucoma treatment. A new app for detecting glaucoma. • App for evaluating the effect of glaucoma on activities of daily living.
88	November/2015	• News: Bono revealed how he had been on glaucoma treatment for 20 years (Hayes, 2015).
87	December/2015	• Media: Fetty Wap's interview about his influence on a 10-year-old boy, in accepting the loss of one eye (Johnson, 2015). • News: Dave Thomas, a former England winger lost all of his peripheral vision to glaucoma (Viner, 2015).

86	Feb/2016	• News: Restoration of sight to a two-year-old who lost eyes to glaucoma (CNN, 2016; Miami Herald, 2016)
87	March/2016	• World glaucoma week with a lot of awareness and screening for glaucoma. • News: The development of contact lens that can improve vision and predict glaucoma (Hall, 2016). • News: Bill Cosby's functional blindness from glaucoma (Heller, 2016)

RQ4: What is the health educational value of information materials available during a surge in online google search for glaucoma over the period studied from 2006 to 2016?

To determine the educational value of glaucoma information available to searchers during the study period, the readability level of the glaucoma information retrieved by individuals in the US during the peak periods identified in figure 4 were evaluated.

A total of 184 websites were evaluated in this study. Of these, 85 met the criteria for inclusion in the study. The 85 websites analyzed were classified according to the source: 58 (68.2%) were registered by commercial organizations (.com and .net), 21 (24.7%) were registered by public interest or non-profit organizations, 5(5.9%) were educational institutions (.edu), and 1 (1.2%) was registered by a governmental agency (.gov). These websites were the same sites that Google searchers found during the periods when surges in glaucoma search occurred. They therefore represent the online educational materials available for learning about glaucoma at the time when this issue came to the forefront in the United States. This study asked:

what grade level of education is needed to understand the information presented by these websites?

The average readability grade level of all the websites was 11.75 ± 1.50. Of the 85 websites, 1 (1.2%) at 7th grade level, 3 (3.5%) at 9th grade level, 10 (11.8%) at 10th grade level, 24 (28.2%) had text written at the 11th grade level, 23 (27.1%) at 12th grade level, 15 (17.6%) at 13th grade level, 6 (7.1%) at 14th grade level, 2 (2.4%) at 15th grade level, and 1 (1.2%) at 16th grade level. All the readability indices, on average, showed that these websites were difficult to understand and required a minimum of 10th to 12th grade education to understand (see Figures 5, 6, 7 and Table 5). Only 3 websites had 7th to 9th grade readability levels. Although these three websites were for public interest, educational or governmental institutions, statistical comparison was impossible because of the low sample size of these organizations.

Figure 6

Pie chart showing the distribution of websites

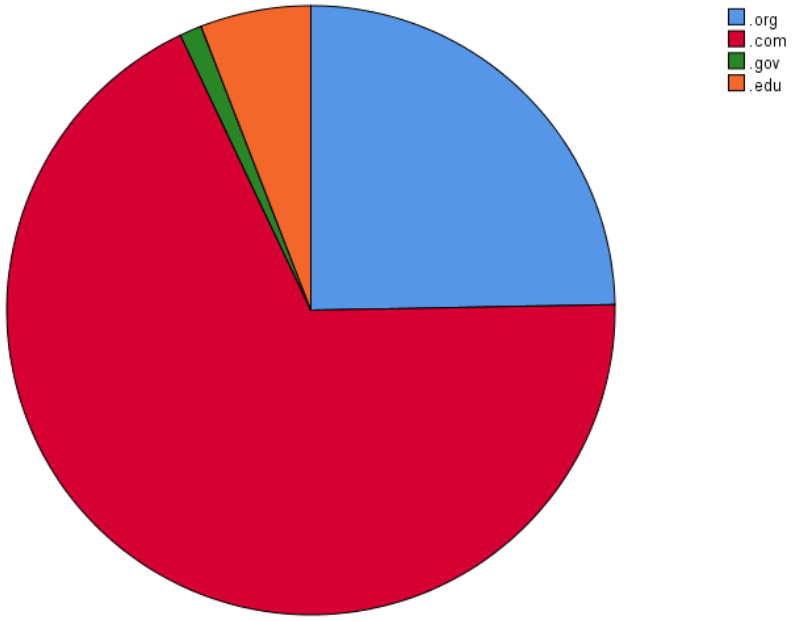


Table 5

The average readability indices of the websites evaluated

Readability Scale	Mean Score	Meaning
Flesch Reading Ease score	49.15 ± 8.0	Fairly difficult
Flesch Kincaid Grade level	10.89 ± 1.75	10^{th} to 11^{th} grade level
Gunning Fog Score	13.28 ± 1.77	13^{th} grade level
SMOG Index	10.19 ± 1.32	10^{th} grade level
Coleman Liau Index	13.39 ± 1.21)	13^{th} grade level
Automated readability index	10.92 ± 2.10	10^{th} to 11^{th} grade level

Figure 7 shows the grade level of glaucoma information presented on the different websites evaluated. The grade level of information varies from grade level 7 to grade level 16.

Figure 7

Bar chart showing the distribution of the grade level of information across websites

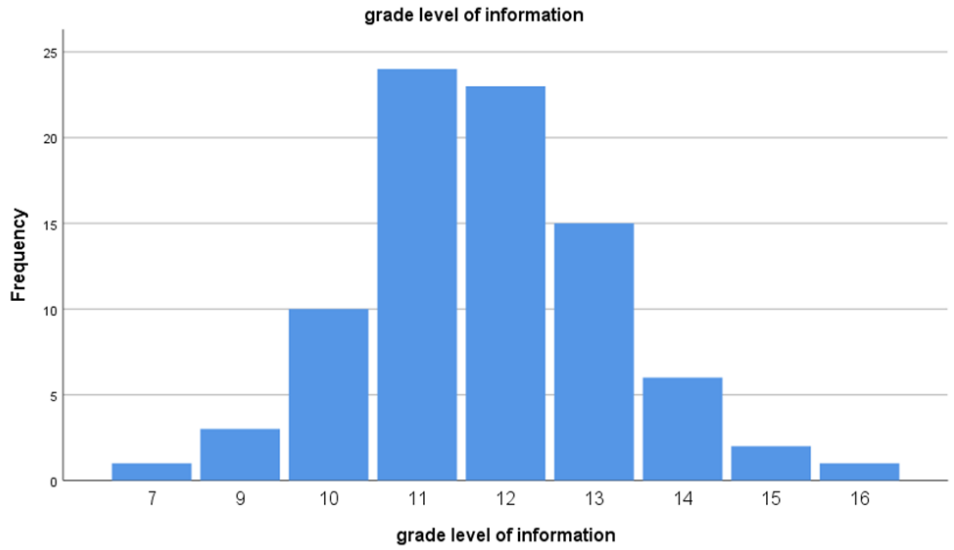
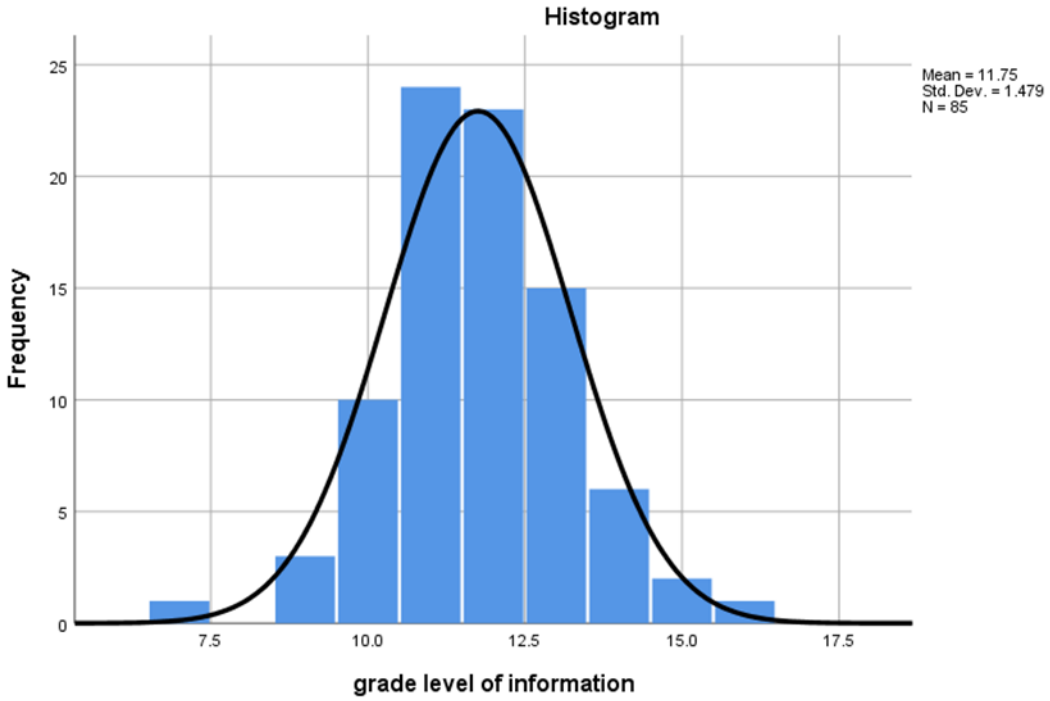


Figure 8 is a histogram showing symmetry of grade level of information across websites. The mean readability of the webpages is 11.75±1.479. This means readers are expected to be able to read at grade levels 10 – 12 to understand the information presented on these websites.

Figure 8

Histogram showing the grade level of information across websites



RQ5: What are the predictors of electronic health literacy levels of African immigrants in the state of Missouri?

This question was answered using the multiple regression analysis. A descriptive analysis of the demographic variables was conducted.

Factors that will predict ehealth literacy include demographic variables and factors such as access to a computer and frequency of online search (Chesser, et al. 2016; Choi & Dinitto,

2013; Richtering et al., 2017). Demographic factors were evaluated in this study. The eHEALS, an 8-item measure of ehealth literacy measures individual's ability to find, evaluate and apply health information obtained electronically to solve health problems (Norman & Skinner, 2006). The eHEALS was administered to the study population to assess their skills and abilities to effectively obtain and use electronically available health information. Data were analyzed using SPSS version 26.0.

Demographic characteristics of participants

A total of 265 participants were recruited into this study. The questionnaire used to obtain participant demographic information have been discussed earlier in chapter 3. All participants were African immigrants or children of African immigrants. The sample consisted of 114 (43%) male and 149 (56.2%) female and 2 (0.8%) individuals who identified as others (n= 2). Participants' ages ranged from 18 to > 65. Participants with ages ranging from 25-34 were more than the other age groups, 29.1% (n = 77). Participants in the age range 18-24 were 11.7% (n= 31), 35-44 were 27.5 % (n= 73), 45-54 were 19.2 % (n= 51), 55-64 were 8.3% (n= 22), and > 65 were 4.2% (n = 11) of the total sample. Of all the participants, 67.9% (n= 180) were married or were in a domestic partnership relationship, 25.3% (n= 67) were single and had never married, 4.5% (n= 5) were divorced and 1.9% (n= 5) were widowed. One of the participants did not respond to the question about marital status (see Table 6).

Table 6

Mean Score on eHEALS by Age, Gender, and Marital Status

Variable	N (%)	*Mean score on eHEALS
Age		
18-24	31(11.7)	30.42
25-34	77(29.1)	29.56
35-44	73(27.5)	30.39
45-54	51(19.2)	32.96
55-64	22(8.3)	28.29
>65	11(4.2)	30.82
Gender		
Male	114(43.0)	30.11
Female	149(56.2)	30.86
Marital Status		
Single, never married	67	29.04
Married or domestic partnership	177	30.92
Divorced, separated	12	31.50
Widowed	5	33.49

The educational level of participants in this study is negatively skewed with 46% (n= 122) of them having above bachelor's degree. A total of 104 (39.2%) of the study participants have associate or bachelor's degree while 7.2% (n= 19) have some college, trade, technical or vocational education. The group with high school or general education diploma (GED) constituted 3.4% (n= 9) of the population while 1.9 % (n= 5) have some high school education, but no high school (HS) diploma. Only 4 participants (1.5%) have no schooling or less than high school education. Two of the participants did not respond to this question (Table 7).

The employment status of the participants in this study is broken down as follows: 67.4% (n= 203) were employed at the time of the interview, 23.9% (n= 72) claimed to be students. Some of the students were employed at the time of the study. It was gathered that 31 out of 72 students (43% of the students) were employed at the time of study. The participants' annual household income is widely distributed across various income groups. 21.1% (n=56) of the participants' household income is 10-30000 annually. 15.5% (n= 41) of the participants earn 31-50000 and another 15.5% earn above 110000. 14% (n= 37) earn 51-70,000 while 9.1% (n= 24) earn below 10000 annually (Table 8).

Table 7

Mean eHEALS score by Educational Levels of Study Participants

Variable	N (%)	*Mean Score on eHEALS
No schooling	3(1.1)	32.00
Kindergarten to grade 8	1(.4)	23.00
Some HS no diploma	5(1.9)	26.40
HS diploma or GED	9(3.4)	29.22
Some vocational training	19(7.2)	31.53
Associate/bachelor's	104(39.2)	30.86
Master's/professional/doctorate	122(46.0)	30.53

Table 8

Mean eHEALS score by Employment Status and Household Income of Study Participants

Household Income	N (%)	Mean eHEALS score
< 10000	24(9.1)	27.71
10000-30000	56(21.1)	29.95
31000-50000	41(15.5)	31.60
51000-70000	37(14.0)	31.97
71000-90000	22(8.3)	30.05
91000-110000	16(6.0)	30.88
>110000	41(15.5)	31.78
Other	28(10.6)	28.68
Employed		
No	62 (23.4)	28.92
Yes	203(76.6)	30.98

Table 9

Mean eHEALS score by Participants' Length of Stay in the United States

Variable	N (%)	*Mean score on eHEALS
< 1 year	27(10.2)	31.12
1-5 years	77(29.1)	28.88
6-10 years	46(17.4)	31.22
> 10 years	98(37.0)	31.22
Born in the US	14(5.3)	31.71

*One-way analysis of variance (ANOVA) of the scores of the different groups showed no significant difference between the groups in their mean ehealth (eHEALS) literacy scores.

Evaluating the access of participants to a computer, 94.7% (251/265) had access to a computer while 4.2% (11/265) had no access. The remaining 1.1% (3/265) did not respond to the

question. For the frequency of online information search, 83.4% of the participants carried out daily search, while 7.5 % did the same about 3-4 times a week. The remaining 9% was distributed between other categories of search. When considering the frequency of online personal health information search, the participants seemed to be distributed across all categories of search, 17.7% (47/265) did daily search, 12.8% (34/265) 3-4 times/week, and 19.6% (52/265) 1-2 times per week. See appendix for the other levels. For the frequency of other health information search, 19.6% (52/265) performed a daily search, 13.2% (35/265) searched about 3-4 times a week, while 12.8% (34/265) searched 1-2 times a week. See appendix for other levels.

More than half of the participants in this study had a family physician while 99/265(37.4%) did not have one. Majority had health insurance; 87.5 % (232/265). When responding to the question about their last visit to a provider, 33.6(89/265) visited, the month prior to this survey, 27.9% (74/265) visited 3 months prior, 24.5%(65/265) visited 12 months prior, while 12.8%(34/265) visited over 12 months before the survey and 1.1% did not respond to the question. See appendix for the table that has these variables.

In Table 10, one-way ANOVA shows a significant difference in the eHEALS score of those who looked up health information on the internet, refilled prescriptions and those who did not.

Table 10

Mean eHEALS score by Online activities of participants in the 12 months prior to study

*Activities	N (%)	Mean eHEALS score	One-way ANOVA (p-value)
Looked up HI on the internet	197(58.8)	31.13	.01
Used chat groups	22(6.6)	30.82	.853
Refilled prescription	17(5.1)	33.88	.042
Scheduled medical appointment	55(16.4)	31.85	.234
Communicated with care provider via email	44(13.1)	31.52	.276

*Some of the participants carried out more than one online activity in the previous 12 months.

Table 11

Online activities by gender

Online Activity	Male	Female
Looked up HI on internet	83	112
Used chat groups	8	14
refilled prescription	9	8
scheduled medical appointment	24	31
communicated with care provider via email	14	30

Table 12 shows that age is negatively correlated with the frequency of online information search. Correlation is significant if $p < .05$. Age did not correlate significantly with the frequency of personal online health information search or the frequency of other online health information search. Also, gender correlates weakly but significantly with the frequency of personal online health information search and the frequency of other online search; male is the reference point. This means that women are more likely to search for information relating to their health compared to men. In this table, the variable "Social media score" was derived by counting how many of eight social media platforms with which a participant is familiar. This score is used as a surrogate for social media engagement. Although this score correlated moderately and significantly with the frequency of online information search, it does not correlate with search for health information online.

Table 12

Pearson's correlations between frequency of information search and some sociodemographic variables

Sociodemo-graphics	Freq. of online information search R (sig 2-tailed)	Freq. of online personal health information search R (sig 2-tailed)	Frequency of other online health information R (sig 2-tailed)
Age	-.174 (.005)	.057 (.368)	.113 (.068)
Marital status	-.095 (.126)	.175 (.005)	.215 (.001)
*Gender	-.031 (.624)	.172(.006)	.133 (.03)
Highest level of education	.228 (.000)	-.154(.014)	.045 (.47)
Household income	.035(.57)	-.073 (.25)	.066 (.29)
Employed	.008 (.901)	.038 (.55)	.075 (.23
Length of US residency	.012(.73)	.035(.58)	.046(.46)
Social media score	.234 (.000)	.034 (.59)	.017 (.79)

Table 13

Pearson's correlations: eHEALS vs some independent variables

Variable	r	p value (*indicates significant correlation)
Age	.051	.412
Frequency of online search	.239	.000*
Frequency of online personal health information search	.195	.002*
Frequency of other online health information search	.205	.001*
Length of US residency	.097	.118
Gender	.055	.38
Level of education	.037	.55
Marital status	.131	.034*
Employed	.127	.040*
Household income	.042	.501

Comparison of study participants with the general population of the United States

Table 14 presents the results of the binomial test done to compare participants in this study with the national and Black population in the US. Comparing participants that reported having access to a computer to the national population, more participants in this study 94.7% reported access to a computer compared to the 88.8% of households in the United States who report access to a

computer (Census Bureau, 2014-2018); this difference is not due to chance $p < .001$. Moreover, 65.1% of Blacks in the United States report access to a computer. The observed proportion of individuals with access to a computer in this sample far exceeds the expected of .651, $p < .001$.

Based on the report from the population of the United States (Census Bureau, 2014-2018), it was expected that 16.5 % participants would report age greater than 65 years. However, 4% of study participants reported they were 65 years and older. The difference in this sample and the national population is unlikely due to chance as $p <.001$. Conversely, there is no significant difference between the proportions of participants with no health insurance compared to the 12.2% of Blacks in the US who have no health insurance. Likewise, there was no difference when the participants, aged 18-64 years were compared with the 13.3% of uninsured adults, aged 18-64 in the national population surveyed in 2018 (Census Bureau, 2014-2018, Cohen, Terlizzi, & Martinez, 2019). The observed proportion is equal to the expected $p = .336$ and $.303 > .05$ respectively.

Also, Table 14 compares the educational level of participants who were 25 years and older in this study with the general US population. It was expected that 87.7% of the participants would have high school diploma or higher (graduate from high school) (Census Bureau, 2018). This was however not the case with the survey participants in this study; 98.3% of the participants reported having a high school diploma or higher. This difference in proportion is not likely due to chance ($p< .001$). In addition, it was expected that 31.5% of the participants would have a bachelor's degree or higher (Census Bureau, 2018). However, the percentage of study participants having above a bachelor's degree is 90.6%. This difference is not likely due to chance ($p < .001$). There is a difference in what was obtained in the sample compared to the population of individuals 25 years and older

Table 14

Comparison of Characteristics of Study Participants with General US Population

Variables		Observed prop	Test proportion	p (p < .05 is significance
Access to a computer	National	.947	.888	.000
	Black population		.651	.000
Individuals who are older than 65 years		.04	.17	.000
Individuals who are 18-64 and do not have health insurance		.111	.122	.336
>25 years who was a HS graduate or higher		.983	.877	.000
>25 years who had above bachelor's degree		.906	.315	000
Males		.433	.508	.009

Reliability and Validity of the eHEALS Tool

Table 15 below shows the reliability and validity of the eHEALS tool. The Cronbach's alpha from this study is 0.927. This measure of internal consistency and scale reliability indicates that the eHEALS measurement tool used in this study is highly reliable in this population. The table shows that the items correlate strongly. The correlations among pairs of items are all strong and positive, ranging from .625 and .827. This provides evidence that the participants in the

study were consistent in their responses on the scale across items. No item appears to be questionable in relation to how it represents the construct of interest. No item on the scale was found to be fit for deletion; Cronbach's alpha if items deleted ranged from .912-.924.

Table 15

eHealth literacy scale (eHEALS) mean items scores and scale reliability

Item	*Mean*	*SD*	*Item-total correlation*
Know what OHR are available	3.89	1.006	.695
Know where to find helpful HR	3.87	1.021	.815
Know how to find helpfulHR	3.95	.976	.789
Know to use the internet to answer HQ	4.02	.920	.784
Know how to use health info	3.98	.871	.801
Have skills to evaluate online health resources	3.81	1.037	.721
Able to determine quality of online HR	3.73	1.053	.665
Confident making HD based on internet info	3.70	1.089	.761
Mean (SD) sum score	30.94	6.499	
Variance	42.239		

Statistical Comparison of eHEALS and Eye-Q Scores among Demographic Groups

Using t-test to compare eHEALS scores, significant differences were found in the mean scores of individuals with access to computers and those with no access to computers ($t_{257} = -3.079$, $p < .01$). Individuals with health insurance also had higher mean eHEALS score than those with no insurance. Similarly, the mean scores of employed individuals is higher than those that are unemployed at the time this study was conducted. Conversely, there were no significant differences in mean eHEALS scores between genders, age groups (less than vs greater than 44), educational levels (Less than High School vs higher than High School; Associate vs Bachelor's and Higher), marital status, and income (below vs above median income of participants) (Table 16).

Similarly, comparison of scores on the Eye-Q test for glaucoma knowledge showed significant differences between participants with access to computer vs those with no access. Compared to individuals between 18 and 44 years old, participants older than 44 had a significantly higher mean Eye-Q score ($p<0.05$). Similarly, participants earning above the median household income have significantly higher Eye-Q scores than those earning at or below median household income. Surprisingly, married participants had significantly higher mean Eye-Q scores than single participants ($p=0.013$) (Table 17). There were no differences among educational levels, gender and employment status. Also, some study participants were exposed to online information on glaucoma (National Eye Institute glaucoma information site) to evaluate the effect of online information on knowledge about glaucoma. A total of 126 participants were involved in this part of the study. Using a paired t-test, the mean score pre-exposure was 4.37 ± 2.471 while the mean Eye-Q score post exposure was 4.98 ± 1.998. The difference between pre-exposure and post-exposure scores is significant (Table 18)

Table 16

Mean, standard deviation and t-test for the score of groups on the ehealth literacy scale (eHEALS)

Variable	Groups compared	Mean eHEALS Score (SD)	p-value (*<0.05 is significant)
	Male	30.11 (7.43)	
Gender	Female	30.86 (6.4)	0.379
	No	24.27(8.89)	
Access to Computer	Yes	30.74(6.72)	0.002*
	18 – 44	30.04(6.83)	
Age	>44	31.48(7.0)	0.118
	No	27.56(7.21)	
Has health Insurance	Yes	30.77(6.83)	0.022*
	Median Income	30.05(6.41)	
Household Income	(51,000 – 70,000)		0.127
	Above Median	31.39(7.03)	
	income		
	No	28.92(6.53)	
Employed	Yes	30.98(6.94)	0.040*

Table 17

Mean, standard deviation and t-test for the score of groups on Eye-Q test

Variable	Groups compared	Mean eye-Q Score (SD)	p-value (*<0.05 is significant)
	Male	4.17 (2.537)	
Gender	Female	4.72(2.385)	0.090
	No	1.90(1.792)	
Access to Computer	Yes	4.60(2.429)	0.001*
	18 – 44	4.20(2.417)	
Age	>44	5.05(2.499)	0.013*
	No	3.60(2.739)	
Has health Insurance	Yes	4.58(2.415)	0.059
	Median Income	4.19(2.474)	
Household Income	(≤51,000 – 70,000)		0.0496*
	Above Median income	4.86(2.516)	
	No	4.70(2.417)	
Employed	Yes	5.05(2.499)	0.013*

Table 18

Changes in Eye-Q Score following exposure to online glaucoma information

	Mean (SD)	Std. Err.	Mean difference	t	Sig. (2-tailed)
Score_pre	4.37 (2.471)	0.220	-0.603	-2.099	0.038*
Score-post	4.98 (1.998)	0.178			

According to the National Eye Institute (n.d), a score of 9 or 10 on the eye-Q test indicates adequate knowledge about glaucoma. This study showed that 3% (8/243) of the respondents to the eye-Q test had a score greater than 9. For scores greater than 5 on the test, 34.3% of the respondents had a score above 5.

Answering the research question 5, a multiple regression analysis that included all the variables related to the research question was employed to predict the ehealth literacy of participants. Most of the independent variables were categorical variables that needed to be recoded before their use in regression analysis. Dummy coding of variables not exceeding four levels and criterion coding of categorical variables exceeding four levels were employed. The variable “age” consists of more than four levels but was dummy coded. The criterion coding involves the coding of category levels using the mean of the dependent variable. In the dummy coding, the categories were coded 0 to 1. Individuals received a code of “1” or “0” depending on if they belonged to a category or not.

The regression model for ehealth literacy was constructed using the backward elimination approach. This approach involves starting with all the predictor variables in the research question and deleting the variables one at a time until further deletion would lead to a significant loss in R square. In this study, the final model was obtained after 26 steps of elimination. The R square changed from 0.349 in the initial model to 0.313 in the final model. The procedure started with 35 independent variables (IVs) and ended with 10 variables (Table 19). The resulting model therefore had ten variables that predicted the score on the ehealth literacy scale and consequently ehealth literacy (Table 20).

Table 19

Correlation of variables in the regression equation predicting ehealth literacy

Variables	Correlation (r)	Beta Weights	p-value
Freq. personal HI search	.214	.154	.014
Freq. online search	.245	.244	.000
Household Income	.193	.149	.013
Degree importance of accessing online HR	.308	.167	.047
Usefulness of internet in making HD	.315	.145	.098
Refilled prescriptions	.129	.101	.089
Age DUM 2(25 – 34)	-.144	-.169	.014
AgeDUM3 (35 -44)	.007	-.155	.023
AgeDUM5 (55 – 64)	-.098	-.161	.010
When sick	-.214	-.198	.001

Table 20

Coefficients for Model Variables for predicting ehealth literacy in African immigrants

Variable	B	t	P value	Partial r	Semi- partial r (part)
Age DUM 2	-.169	-2.477	.014	-.169	-.142
Freq. personal HI search	.154	2.480	.014	.169	.142
Freq. online search	.244	4.029	.000	.268	.231
Household Income	.149	2.493	.013	.170	.143
Degree importance of accessing online HR	.167	1.995	.047	.137	.114
Usefulness of internet in making HD	.145	1.663	.098	.114	.095
Refilled prescriptions	.101	1.707	.089	.117	.098
Age DUM 3	-.155	-2.284	.023	-.156	-.131
Age DUM 5	-.161	-2.608	.010	-.178	-.150
When sick	-.198	-3.278	.001	-.221	-.188

Regression model for the prediction of score on the ehealth literacy scale is given by the following simple regression equation:

$Y' = \alpha + b_1X_1 + b_2X_2 + b_3X_3 \ldots\ldots + b_kX_k + e$

Where:

α is the intercept or constant

Y' = score on ehealth literacy scale

b or β = the regression coefficient

X = the observed score

$Y' = \alpha + b_1X_1 + b_2X_2 + b_3X_3 \ldots\ldots + b_kX_k + e$

AgeDUM2, AgeDUM3 and AgeDUM5 = 1, AgeDUM2 = age between 25-34

AgeDUM3 = age between 35 and 44, AgeDUM5 = age between 55-64

A comparison of the standardized beta weights reveals that all the variables in Table 20 statistically significantly predict ehealth literacy score, except for the online activity of refilling prescriptions and the feeling that the internet is a useful tool in making health decisions, p = .098 and .089 respectively > .05.

AgDUM3 and AgDUM5 have the least linear correlation coefficient with the score on the ehealth literacy scale. Their linear correlation coefficients (zero order correlation) were .007 and -.098 respectively, which were very weak. The negative correlation signifies that as age increases, the score on the ehealth literacy scale of the sample participants decreases. However, their contributions to the variance in the eHEALScore is significant at .023 and .010 <.05

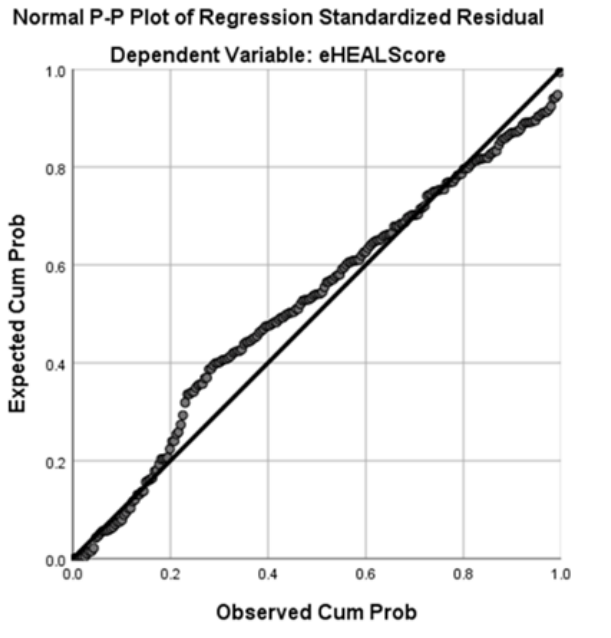
respectively. They had a bivariate correlation coefficient of -.156 and -.178 respectively and semi-partial correlations of -.131 and -.150. Their tolerance of .712 and .863 respectively, show high relationship with the dependent variable and low relationships with the other independent variables. The Variance Inflation Factor are low at 1.404 and 1.519 indicating minimized collinearity with the other variables in the model; hence, the retention of these variables in the model.

The R and R^2 provide information about the relationship and the amount of overlap in variance between the ehealth literacy score and the independent variables. R is the strength of the relationship between the eHEALS score and the independent variables, while R^2 is the percent of variance in ehealth literacy score accounted for by its linear relationship with the different IVs. R = .559, R^2 = .313.

Thus, the 10 independent variables chosen accounted for 31.3% (value of R^2) of the variation in the ehealth literacy score. F statistic for the final model was 9.510, $p < .001 < .05$ (Figure 8)

Figure 9

Normal plot for eHEALS Score



RQ6. Does ehealth literacy predict the knowledge of African immigrants about glaucoma?

A simple regression analysis was used to determine if ehealth literacy can predict an individual's score on the eye-Q test.

Table 21 gives Pearson correlation coefficient, r = .294, which implies a moderate correlation between the ehealth literacy score and the eye-Q test score. R^2, the coefficient of determination of .087, indicates that approximately 8.7% of the variance in the eye-Q test score can be accounted for by score on the ehealth literacy scale. This can indicate that the ehealth literacy of the participants has a weak effect on their knowledge of glaucoma, which the eye-Q test is based on.

Table 21

Summary of the regression model predicting eye-Q test score from eHEALScore

Model	R	R^2	p-value
1	.294	.087	.000

The coefficient table (Table 22) gives the raw score beta which indicates that the eye-Q test score changes by .104 for every point increase in the eHEALScore. Beta is positive, so the eye-Q test score increases as the eHEALS score increases (Figure 9).

Table 22

Coefficients for Model Variables for predicting eye-Q test score from ehealth literacy score

Unstandardized coefficient			Standardized Coeff		
	B	Std.error	Beta	t	p-value
Constant	1.308	.677		1.932	.055
eHEALScore	.104	.022	.294	4.777	.000

The simple regression equation $Y' = \alpha + bX + \ldots\ldots e$ ------(1)

Where α is the intercept or constant

b or β = the regression coefficient

X = the observed score

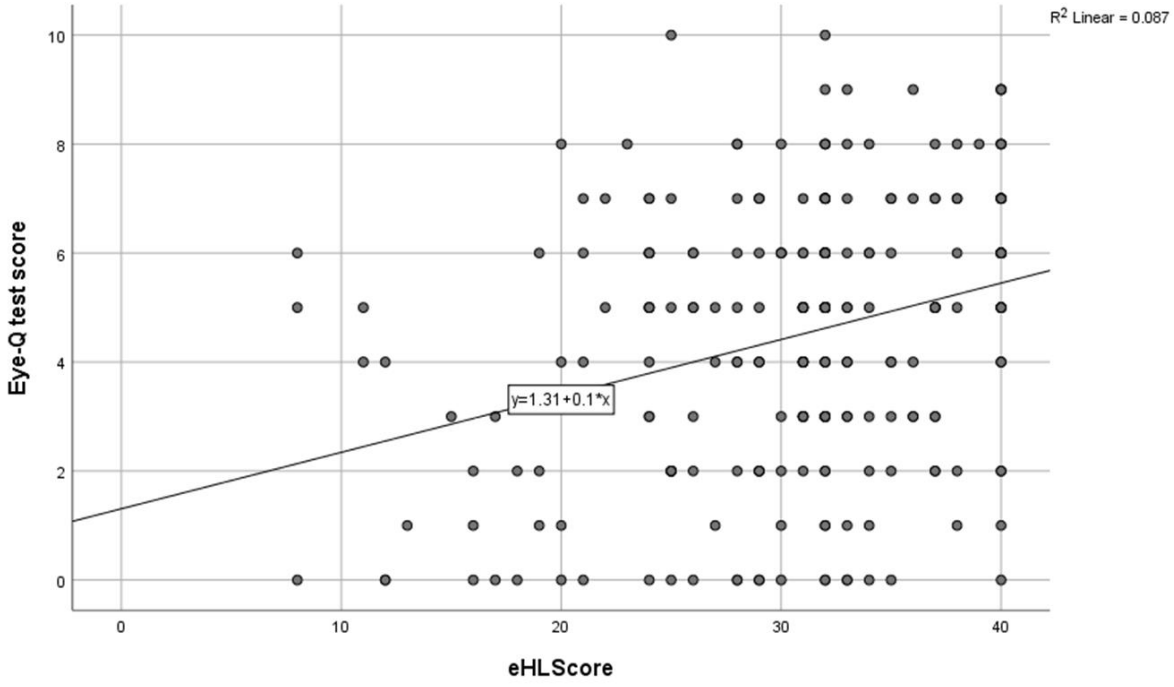
From the table, our regression equation can be written as:

$Y^{'} = 1.308 + .104$ (eHEALScore)

Eye-Q test score = 1.308 + .104 (eHEALScore)

Figure 10

Scatter plot for the prediction of eye-Q test score on eHEALScore



X = score on the ehealth literacy scale

RQ7: What are the factors that predict glaucoma knowledge in African immigrants in the US?

A multiple regression analysis of the independent variables used in the study was conducted to determine the variables that significantly predict knowledge about glaucoma. Most of the independent variables were categorical variables that needed to be coded before their use

in regression analysis. Dummy coding of variables not exceeding four levels and criterion coding of categorical variables exceeding four levels were employed. The criterion coding involves the coding of category levels using the mean of the dependent variable. In the dummy coding, the categories were coded 0 to 1. Individuals receive a code of "1" or "0" depending on if they belong to a category or not.

To build the regression model for eye-Q test score, the backward elimination approach was applied. All the predictor variables in the research question were started with and the variables were deleted one at a time until a loss in R square was significant. The final model was arrived at, after 26 steps of variable elimination. The r square changed from .320 in the initial model to .276 with the last model. The procedure started with 35 independent variables (IVs) and ended with 10 predictors. The F change decreased from 2.105 to 1.880. The loss of independent variables from one step to the other was not significant. The resulting model had three variables that had zero included in the interval for the b coefficient. (Table 23).

Table 23

Correlations and standardized beta weights for variables in the regression equation

Variable	Correlation	Beta Weights	P value
eHEALScore	.274	.202	.002
Employed	-.058	-.157	.021
Gender	.138	.164	.009
Household income	.203	.175	.011
Freq. online info search	.209	.160	.012
Freq. of personal health info search	.158	.114	.086
Freq other online health info search	.238	.122	.070
Last visit to provider DUM1	.095	.166	.008
AgeDUM2	-.247	-.182	.005
Used chat groups	-.084	-.139	.026

Table 24

Coefficients for Model Variables for predicting glaucoma knowledge in African immigrants

Variable	B	B	t	P value	Partial r	part r (part)
eHEALScore	.073	.202	3.095	.002	.216	.188
Employed	-.949	-.157	-2.335	.021	-.164	-.142
Gender	.823	.164	2.636	.009	.185	.160
Household income	.824	.175	2.553	.011	.179	.155
Freq. online info search	.875	.160	2.535	.012	.178	.154
Freq personal online health info search	.784	.114	1.726	.086	.122	.105
Freq. of other online info search	.525	.122	1.822	.070	.129	.111
Last visit to providerDUM1	1.250	.166	2.663	.008	.187	.162
AgeDUM2	-.993	-.182	-2.862	.005	-.200	-.174
Used chat groups	-1.116	-.139	-2.244	.026	-.158	-.136

From the above, it follows that for every unit increase in eHEALScore, there is an increase of .073 on the eye-Q test score. A change in employment from employed to unemployed yields a decrease of .949 on the score. For gender, male = 0 and female = 1, For a change in gender from

male to female, there is an increase in score by .823. There is a unit change in eye-Q test score for every unit change in the independent variables included in the regression model in Table 24.

The resulting model therefore is:

Eye-Q test score = $-\beta_0 + b_1X_{eHEALScore} - b_2X_{employed} + b_3X_{gender} + b_4X_{hhincome} + b_5X_{freqonlinesearch} + b_6X_{freqpersonalHI\ search} + b_7X_{freqotheronline\ search} + b_8X_{LVDUM1} - b_9X_{AgDUM2} - b_{10}X_{used\ chat\ grps.\ ...}$equation (3)

Eye-Q test score = glaucoma knowledge = $-\beta_0$ + .073 (eHEALScore) - .949(employed) + .823 (gender) + .824 (hhincome) + .875 (freq. of online search) + .784 (freq. of personal HI search) + .525 (freq of other online search) + 1.250(LVDUM1) – .993(AgeDUM2) – 1.116 (used chat groups)...equation (3a)

LV_DUM1 = last visit to a provider = last 12 months =1, other visit times = 0

AgeDUM2 = age 25 to 34 =1, all other age categories = 0

Employed = 1, unemployed = 0

Gender = Female = 1, male = 0

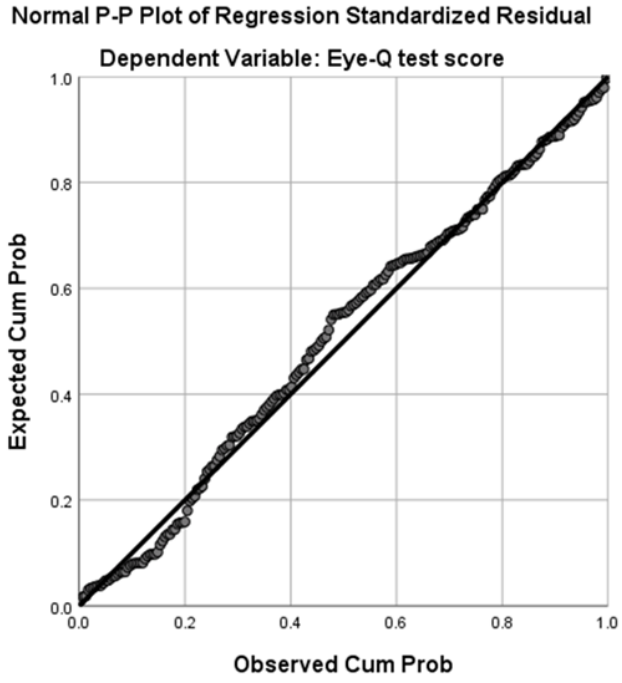
R for the final model was .525.

R square = .276, which means that the variables in the model only accounts for 27.6% of the variance in the eye-Q test score = glaucoma knowledge.

Figure 11

P-P plot for normality

Testing for normal distribution of sample and closeness of data points to theoretical best fit



CHAPTER 5

DISCUSSION, LIMITATIONS, SUMMARY, AND RECOMMENDATIONS

This chapter presents a discussion of the study findings, implications of the findings, summary of findings and recommendations for improving the dissemination of online patient educational materials. This section also provides recommendations for future research.

Purpose of the Study

It has been estimated that the prevalence of glaucoma in African Americans ranges from 4% in people aged 50 – 59 to 13% in those aged 80 – 89 years old. These rates are consistently higher than the 2% - 3% prevalence rate reported among equivalent age groups in the general population of the United States (Tielsch, Sommer, Katz, Royall, Quigley & Javitt, 1991). It has therefore been suggested that individuals of African ancestry may carry a genetic predisposition to glaucoma (Racette, Wilson, Zangwill, Weinreb, & Sample, 2003). The past decade has seen a dramatic increase in the number of African immigrants to the United States; they now constitute about 5% of the US population (Anderson, 2017; Omenka, Watson & Hendrie, 2020). A study in Minnesota, where African immigrants now constitute approximately 2% of the state's population have suggested that this group may face impediments that include language barrier and difficulty in navigating the healthcare system (Cernasev et al., 2020), suggesting low health literacy among African immigrants compared to the general population of the United States. The health literacy of African immigrants in the United States has not been extensively studied, neither has their use of the internet as a source of health information previously explored. Thus, the purpose of this study was to evaluate the health literacy of African immigrants living in the state of Missouri, evaluate their use of the internet and social media as information source, and determine the

factors that may predict their knowledge of glaucoma. Additionally, this study will determine the trend of online information search about glaucoma over a period of 10 years from 2006-2016, identify the triggers of observed surges in glaucoma information search, and evaluate the quality of the information available to online information seekers during each surge in the search for glaucoma information.

Research Questions

To achieve the stated goals of the study, the following specific research questions were used:

1. What type of glaucoma information do individuals search on the internet using the google search engine?
2. What is the trend of online search for glaucoma information using google over the 10-year period from 2006-2016?
3. What are the triggers for an increase in online search for glaucoma when spikes in searches were observed from 2006-2016?
4. What is the health educational value of the information materials available during a surge in online google search for glaucoma over the period studied from 2006 to 2016?
5. What are the factors that predict the ehealth literacy of African immigrants in the state of Missouri?
6. Does ehealth literacy predict the knowledge of African immigrants about glaucoma?
7. What factors will predict knowledge about glaucoma in African immigrants in the state of Missouri?

A brief discussion of the findings:

Research Question 1. What type of glaucoma information do individuals search on the internet using the google search engine?

Google Trends is a search interface that allows interrogation of a database of search queries done through the Google search engine from 2004 onwards. This database allows a search to determine the volume of interest in a topic over time. The volume is expressed as relative volume: the highest relative volume of hundred is reserved for the volume at the time when a search term is most searched; every other search is benchmarked against this maximum volume. The total search for a topic is expressed as Search Volume Index (SVI) or relative search volume, which is a normalized quantification of a search topic relative to all other Google searches in a given time frame (Hsiang et al., 2018). Data obtained from Google Trends have become very useful in understanding the epidemiology of several diseases since search patterns have been used to estimate the incidence of several diseases in a population (Cho et al., 2013; Hoerger et al., 2020; Mavragani & Ochoa, 2019). This tool has become a useful source for evaluating the forms of information sought by individuals online to track disease symptoms and prevalence of diseases.

Google Trends was used in this study to evaluate the type of glaucoma information individuals searched for on the internet between 2006 and 2016. The results of this study indicate that most of the individuals who searched for information on glaucoma using the Google search engine did so to understand glaucoma in its entirety; what it is and the different forms of the disorder. The terms entered to search for the different forms or types indicates a deficiency in glaucoma knowledge. In addition, searchers desired to understand the symptoms, treatment,

causes, medications, and if marijuana could be used to treat the disease. It is obvious from these searches that the individuals searching for information about glaucoma wanted to know about the disease, how they can know if they have it or guide against having it, and how it can be managed if diagnosed with it.

The most searched term was “glaucoma” itself. This large search number could be because glaucoma is not a disease that is widely and commonly discussed. Hence, glaucoma information unlike other diseases like hypertension, heart failure, angina, inflammatory bowel disease or cataract is not easily available unless a deliberate effort is made to search for it. This suggests a need for more and easily available information on glaucoma. These findings agree with the results of the study conducted by Brigo and Trinka (2015) to determine the terms most often used to search for information about status epilepticus (SE). Brigo and Trinka’s study showed that individuals seeking to know about SE desired to know how it is described, the different forms of the disease, and how it can be managed.

The other terms searched for that were popular during the period studied were “Fetty Wap”, “Fetty Wap eye”, ICD 9 and ICD 10. The search for “Fetty Wap” or “Fetty Wap eye” suggests the influence of Fetty Wap’s revelation of his glaucoma diagnosis. This showed the impact of celebrity on glaucoma awareness in the US population. Fetty Wap is a celebrity who revealed to his fans that he lost one of his eyes to congenital glaucoma. It is assumed that people searched for this celebrity’s name in relation to the eye, because the term glaucoma was not a familiar term that could easily be remembered by a lot of people.

The search for the international classification of diseases (ICD) 9 or 10 related to glaucoma was also high. ICD refers to the classification of “morbidity data from the inpatient and outpatient records, physician offices and most National Center for Health Statistics (NCHS)

surveys" (NCHS, 2020, para. 3). The ICD is used to classify diagnoses made by health care providers and the reasons for visits of patients. This helps in the coding of diseases for billing purposes and diagnoses made. The increase in their search volumes could mean that medical coders were not familiar with the codes for this disease and had to search online to bill diagnosed individuals appropriately. Health care providers might also be checking online for appropriate codes for this disease. This increase in search for the medical code could also mean an increase in the diagnosis of the disease during this period. Hassid et al. (2017) in their study found a correlation between the search for gastrointestinal symptoms and the hospital presentation and diagnoses of patients with gastrointestinal symptoms.

Research Question 2. What is the trend of online search for glaucoma information using google over the 10-year period from 2006-2016?

Research Question 3. What are the triggers for an increase in online search for glaucoma when spikes in searches were observed from 2006-2016?

From Figure 4, it is apparent that the search for online glaucoma information was stable over time, with occasional spikes. This means that the general interest in glaucoma information was constant over time, until there was a news item to stir interest or curiosity about the term. This interest resulted in increase in volume of search for glaucoma information and consequently a spike on the graph. The periods of peaks or spikes on the graph of the frequency of search for glaucoma against time in years, corresponded to news about celebrities announcing their diagnosis with glaucoma or how they have lived with the eye disease. Periods of peaks also corresponded with news of legislations that affected individuals living with glaucoma and when there were breakthroughs in glaucoma research or management. The highest peaks obtained,

which were >98% search volume, corresponded with news about one celebrity or the other announcing their diagnosis and life with glaucoma.

Previous studies have shown that the revelation of a celebrity's diagnosis of a disease to fans promoted the awareness of people about the disease communicated and, consequently, the search for information about the disease (Lancucki, Sasieni, Patnick, Day & Vessey; 2012, Langer, Zimmerman, Herdershot & Singh, 1992). The announcement of Paul David Hewson (known as "Bono" on stage) about his diagnosis with glaucoma in October 2014, led to a five-fold increase in the search for glaucoma information in Ireland while the search for glaucoma doubled in the United Kingdom (Lyons et al., 2017). In the US, this message steered the online search for glaucoma information in the upward direction with search volume rising to 98%. Likewise, the diagnosis of Roseanne Barr and the revelation of Fetty Wap about his congenital glaucoma led to an increase in online glaucoma volume search.

In addition, the periods of peaks were associated with March and April, the month in which there is glaucoma awareness week and the month after it. The periods of peaks on the graph were also associated with other news events, apart from celebrity news related to glaucoma. For example, the news about dogs having glaucoma and the increased risk of having glaucoma in those who keep cats as pets led to a spike in searches for glaucoma. Similarly, news related to legislative actions taken about driving when an individual has a visual impairment related to glaucoma and other eye diseases led to a spike in glaucoma search. Likewise, passing of a bill that allows the use of marijuana in the treatment of glaucoma resulted in a spike. These findings agree with other studies that have shown that the news coverage of a disease is associated with the search for information about that disease (Dehkordy et al., 2014; Niederdeppe et al., 2008). Dehkordy and his colleagues (2014) correlated the news coverage of

the introduction of a bill affecting the screening for dense breast to an increased search for information on dense breasts.

Research Question 4. What is the health educational value of information materials available during a surge in online google search for glaucoma over the period studied from 2006 to 2016?

With the growth of internet use and the dependence of individuals on available information on the internet for making health decisions, online information available to glaucoma patients were assessed for easy comprehension by the target audience. The information available from 85 of the 184 websites retrieved by online searchers during periods of surges in glaucoma search between 2006 and 2016 were assessed for their ability to be easily understood by readers. The results show a high readability grade level of 11.75. This means that on average, the reading grade level of glaucoma online information evaluated was at the 11^{th}-12^{th} grade level. In addition, the average score was 49.15 on the Flesch Reading Ease score. This score indicates the information on the websites were difficult to understand. This shows that Google searchers, on average, were accessing information they might not have understood and, therefore, might not be able to make appropriate health decisions using the information obtained.

From all the websites accessed, only one was from a governmental organization, five were from an educational institution, while the remaining 79 websites were from commercial and public websites. The average grade level of the information provided by the governmental website was 9, while that of the educational institution was 9.80. Also, the information provided by the commercial organizations' website was at the 11.91 grade level while the not for profit organizations' websites had information at the 11.90 grade level. The ease of reading the governmental website glaucoma information was 64.60, which was within the recommended reading ease of educational materials (Readability Formulas, 2020). This government website

was the website with the highest score out of all the websites evaluated in this study. Only 4.7% of the total websites evaluated in this study had information at a grade level below 10, meaning 95.3% presented information at the 10th grade level and above.

Having just one governmental and five educational websites information retrieved during this study was concerning, as it shows minimal interest by governmental agencies and educational institutions in educating citizens about glaucoma. It is not clear if the same holds for other eye diseases like cataract and macular degeneration. The information from these websites is expected to be more reliable and accurate compared to the public and commercial websites as they are not putting the information out there for any immediate commercial gain.

This study showed that a readability grade level of information at between the 11th and 12 grade level is too high for US citizens with 90 million of its population reading at the sixth-grade level (Chew, 2009). If health information provided online is consistently provided at levels above the reading grade level of the readers, then the information would not be beneficial. Only one website had glaucoma information at the seventh-grade level. The reading ease score of this website was 74.9 which is regarded as fairly easy to understand. With only one website providing information at the level that meets the need of the general population, a lot of individuals seeking information from these websites are not provided with easily understandable information needed to aid them in making appropriate health decisions. This consequently leads to confusion about their diagnosis, medication incompliance, self-misdiagnosis and lack of prompt visit to a healthcare provider. When there is non-compliance, this leads to loss of vision and subsequently loss of independence and inability to carry out activities of daily living and increased burden on the health care system.

The average readability level of websites accessed in this study is at the 12th grade level, which is above the recommended 6th grade level (Hutchinson, Baird & Garg, 2016; Weiss, 2007). The results of this study are similar to the mean 12th grade level that was obtained in the study conducted by Jayaratne, Anderson, Zwahlen (2018) on websites that provided information on dental implants. The mean Flesch Kincaid grade level (FKGL) of all the websites in this study was 10.89 (SD 1.75). This is much lower than 12.19 (SD 2.20) that was obtained by Guo et al. (2018) when the websites that provided online information on unsuccessful spinal surgery was evaluated. Similarly, a systematic review of the literature that involved an evaluation of 950 educational materials including websites, targeted at ophthalmic patients revealed that the educational materials were regularly above the comprehension levels of the readers (Williams, Muir & Rosdahl, 2016). Taken together, these studies, including the present one, showed that online websites consistently provide health information above the level of comprehension of a very high percentage of the US population.

Research Question 5. What are the factors that predict the ehealth literacy of African immigrants in the state of Missouri?

Of the participants in this study, 80.8% indicated that the internet was useful to them in making health decisions and 87.7% of the participants found the internet very important in accessing online health resources. This agrees with the findings of the Pew research center in 2020 that 87% of adults in the US indicated that the internet is essential and important to them during the pandemic in obtaining health information.

When participants in this study were exposed to online glaucoma information, that was available on the National Eye Institute website, there was a significant difference in their score on the glaucoma eye-Q test when their score on the test before the information exposure was

compared with their score after exposure, p = .038. Providing information to individuals about a disease seems to be effective in improving their knowledge about the disease. Adequate knowledge about a disease empowers individuals to effectively manage their care.

The participants in this study were African immigrants to the US. The length of stay of participants in the US varied from less than one year to greater than 10 years. Some of the participants were children of immigrants. They were born in the US and they constitute about 5.3% of the total participants. The participants in this study vary from the national population in their distribution of gender. There were more females (56.2%) than males (43.0%). The mean score of participants on the ehealth literacy scale vary across age groups, with 45-54 age group having the highest score of 32.96. One-way ANOVA of the mean score on the ehealth literacy score indicated no significant difference among the different age groups. The mean scores for groups according to educational attainment, household income, gender, length of US residency and marital status were also found to be non-significantly different using one-way ANOVA.

Based on age, the participants in this study differ from the general US population; 89% were less than 65 years of age. This could account for the average score of 30.94 on the eHEALS for this group, which was significantly higher than the mean score of 24 obtained in the study conducted on lung cancer survivors who were older on average (Milne et al., 2015). This mean score on the eHEALS was also higher than was obtained in the investigation conducted by Richtering et al (2017) on cardiovascular patients, where the mean score was 27.2. The mean score of the present study is higher than the score (greater than 26) set by Richtering et al. (2017) as indicative of high ehealth literacy. However, comparing the average eHEALS score of this study to what James and Harville (2016) obtained in the study conducted on 881 African

Americans in the US showed no significant difference. The average score from this study was 30.94 ± 6.89 and the average from their study was 30.4 ± 7.8 (James & Harville, 2016).

Similarly, comparing the response of the participants in this study with the study conducted by Milne et al (2015), 81.5% of the participants in this study agreed with the statement "I know how to use the Internet to answer my questions about health", while 47.6% agreed in the other study. The mean score for that item in this study was 4.02, which was similar to 4.0 obtained by James and Harville in their study

Correlation analysis of the variable "length of residency in the US" with score on the ehealth literacy scale using Pearson's correlation showed no correlation (.097, $p > .05$). A similar study (Martins et al., 2009) examining the general population of the United States showed that the shorter the length of residency in the United States, the lower the health literacy scores of participants. However, this study found no association between length of residency in the US and ehealth literacy score of participants. Conversely, other bivariate analysis conducted, showed significant positive relationships between the frequency of online search and ehealth literacy score. This was similar to the findings of Richtering et al. (2017) on cardiovascular patients. Likewise, van der Vaart et al. (2011) had similar conclusions from their study on a stratified sample of the Dutch population and a sample of patients with rheumatic disease. The researchers discovered that the frequency of information search on the internet was a major predictor of ehealth literacy score.

Also, this agrees with the works of Chesser et al. (2016), Choi et al. (2013), and Zhang et al. (2017) on the use of health information technology. The results of this study indicated that age, gender, level of education and household income had no observable significant correlation with scores on the ehealth literacy scale. van der Vaart et al. (2011) similarly indicated that no

correlations were obtained between age and education and ehealth literacy score. Likewise, Richtering et al. (2017) in their study concluded that age, gender, education, and income do not correlate significantly with ehealth literacy score.

Though age and household income did not correlate with the ehealth literacy score, these variables in the presence of other variables significantly predicted the ehealth literacy score in the multiple regression analysis conducted in this study. The multiple regression analysis carried out showed that age, household income, online search for personal health information, and online search for general information predicted eHEALS score in this study. In addition, the higher the individuals value the importance of health resources and the more individuals perceive the internet as a useful tool in making health decisions, the more likely their score on the eHEALS will be high. Other variables that predicted eHEALS score in the population studied were refilling prescriptions online and visiting the healthcare provider when sick.

In this study, in the presence of other variables, age correlates independently, negatively with ehealth literacy score. This agrees with the findings of other studies where older age was found to predict lower ehealth literacy score or (Richtering, et al. 2017; Zhang, et al., 2017; Choi, et al. 2013) or health literacy (Martin, et al, 2009). In this study, individuals older than 65 were not likely to have a high score on the eHEALS. The result obtained for individuals older than 65 agrees with the literature (Richtering, et al., 2017; Tennant, et al., 2015). The results obtained for the 18-24 age level, however, contradicts previous works that showed that younger individuals tended to score higher on the eHEALS. In this study, the frequency of their online search is high, but they are less likely to be able to evaluate the different websites for their quality and accuracy. This discrepancy was previously explained by Chesser, et al. (2015) in their study that the amount of time spent on the internet does not improve an individual's eHEALS, but the time

spent using online health-related resources. In this study, 80.6% of this age group is likely to look up health information online. However, only 19% of them used it to schedule a medical appointment and 9.6% used it to communicate with their care providers. This proportion is lower than was obtained for the other age groups in this study.

All variables were statistically significant in this model except for refilling prescriptions and the usefulness of internet in making health decisions. Having the frequency of online search in the model here, agrees with the findings in the study carried out by Richtering, et al (2017), where time spent on the internet was a significant predictor of ehealth literacy. In this study, sociodemographic variables like educational status, marital status, employment status, length of residency in the US and gender were not included in the predictors of ehealth literacy. There are conflicting literature regarding the inclusion of gender and marital status in the list of ehealth literacy predictors (Tennant, et al., 2015).

Research Question 6. Does ehealth literacy predict the knowledge of African immigrants about glaucoma?

The bivariate correlation coefficient between ehealth literacy and score on the eye-Q test was .294, $p < .001$. The coefficient of determination, R square = .087 = 8.7%, which shows that ehealth literacy only accounts for 8.7% of the variance in the eye-Q test score. This indicates that ehealth literacy has a weak effect on eye-Q test score. It can therefore be inferred that electronic health literacy does not have a great influence on the score of an individual on the eye-Q test. This means that being ehealth literate does not equate to being knowledgeable about glaucoma and other diseases. It follows that one has to be motivated to seek information about diseases either out of interest or curiosity stirred by the news media, or the fact that one or a relative has been diagnosed with the disease.

Research Question 7. What factors will predict knowledge about glaucoma in African immigrants in the state of Missouri?

The score on the eye-Q test is equivalent to knowledge of glaucoma. The eye-Q test is used to assess glaucoma knowledge (NEI, 2020). Only 3% (8) of the study participants who completed the eye-Q test had scores above 9, the cut-off score for adequate glaucoma knowledge (NEI, n.d). The variables included in our final model for predicting the score on the eye-Q test include: employment status (being employed), gender (male or female), household income, frequency of online information search, last visit to provider was 12 months prior to study, age, and the use of chat groups. All were statistically significant in their prediction except for the frequency of personal online health information search and the frequency of searching other online information. The results of this study showed that with increase in the years of employment, there is a decrease in the score on the eye-Q test. Similarly, an increase in the use of chat groups is associated with a decrease in the score on the eye-Q test.

Limitations

The search terms in this study were aimed at capturing the interest of searchers about glaucoma. It was however difficult to determine or evaluate what actually motivated these different users to search for information on glaucoma. It was impossible to ascertain if users were individuals who were newly diagnosed with glaucoma, or individuals who were already living with glaucoma, or family or relatives of patients living with glaucoma or just those who were seeking to know about the disorder out of curiosity after reading or learning about it in the media. It would have been interesting to be able to ascertain the motivation for internet searches

for glaucoma during the study period. This would allow appropriate timing and targeting of glaucoma education.

The readability levels of the websites were evaluated. The quality and accuracy of the online information about glaucoma were not evaluated. The graphics presented with glaucoma information were not evaluated for their effects in educating those who visit the website about glaucoma. Evaluating the effect of these graphics might be effective in making the information on glaucoma websites easier to understand.

The reduced strength of the relationship obtained for the correlational analysis in this study may have been related to the different types of variables, categorical and continuous. Bertani, Paola, Russo and Tuzzolino (2018) stated in their article that the quality of the correlation between two variables may be altered by the types of variable being correlated.

One of the limitations of this study is that the population in this study differs significantly from the US population in educational status and attainment. About 46% of participants have above bachelor's degree, which is significantly higher than the 31.5% that exist in the US population. Also, 98.3% of the study participants have educational level above high school or higher. This is significantly higher than the 87.7% that is in the population (census Bureau, 2018). Additionally, the percentage of participants in this study who were 65 years and older were 4% which was significantly lower than the 16.5% ($p < .001$) that exists in the general US population.

Also, the gender distribution of study participants was significantly different from the general population. The participants were mainly females, 56.7%, while males were 43.3%. This proportion of males is less than the 50.8% that exists in the general population, $p < .05$. Also,

88.3% of the participants recruited had above high school education while 80% had associate/bachelor's degree and above. The participants are not a good representation of the population under study. They are individuals who volunteered to participate in the study, which could have resulted in oversampling of individuals with certain characteristics more than others. Furthermore, the study was focused on African immigrants in the US. Therefore, the results of this study may not be generalizable to other populations.

Summary

This study showed that individuals in their quest for online information on glaucoma search for information relating to the term "glaucoma", the different types of glaucoma, symptoms of glaucoma, and the different treatment modalities. In addition, people searched for "Fetty Wap" or "Fetty Wap eye" because Willie Junior Maxwell, nicknamed Fetty Wap, (Wikipedia, 2020) lost one of his eyes to congenital glaucoma (Markman, 2015). The search for glaucoma was greatly influenced by the announcement of celebrities like Roseanne Barr, Bono and Fetty Wap. In addition, the news influenced the search for information on glaucoma.

This study found that the readability of the information available at the peak times of glaucoma information searches from 2006 to 2016 was beyond the level of understanding of the readers. The information was provided at an average grade level of 12, which is higher than the recommended grade level of seven. It was also noted in this study that only one of the 85 websites evaluated was a governmental website. Thus, glaucoma information is provided by websites with commercial rather than public interest, and at a level higher than what an average reader in the US can understand.

This study sample revealed that 24.4% of the participants in this study scored less than 26 on the eHEALS, while the remaining 75.6% had scores above 26. It had been established in previous studies that scores less than 26 on the eHEALS is considered low on the test (Richtering, et al., 2017). This shows that a huge proportion of the participants have high eHEALS. However, eHEALS was not predicted in this study by the educational attainment of participants, their marital status, employment status or length of stay in the US. Thus, African immigrants in Missouri, although highly educated, and with high ehealth literacy, may not have adequate knowledge about glaucoma, a chronic eye disease that is prevalent in the Black population.

Similarly, the high proportion of participants that scored high on eHEALS did not translate to knowledge about glaucoma. Scores of 9 to 10 on the eye-Q test were regarded as equivalent to having good knowledge about glaucoma. Out of the 243 (22 were missing) participants who completed this part of the survey, 8 (3.3%) had a score of 9 to 10. Indeed, only 34.4% of the participants in this study had a score above 5 out of 10. This indicates that despite high educational status and high eHEALS (average score 30.94 ± 6.5), African immigrants are deficient in their knowledge of glaucoma.

Implications of Study Findings

This study described a population with high ehealth literacy. However, the population have an inadequate knowledge about glaucoma. Thus, evidence of exposure to online information does not necessarily translate to sufficient knowledge about a disease to which this population is known to be susceptible. Although this is a small sample of the Black population in the United States, the findings in this study showed that a high level of education does not close the information gap about glaucoma in this population. Nonetheless, their high level of ehealth

literacy presents a significant opportunity to tailor glaucoma education to this population via online learning programs.

In addition, evaluation of online glaucoma information in this study showed a major defect that should be addressed quickly to ensure that online platforms could become useful in glaucoma education. Unlike other diseases like hypertension, diabetes, and heart failure, glaucoma is not widely addressed by non-commercial sources online. This study showed that the online information provided by these sources are presented at levels above what could be easily understood by an average reader. This implies that a major platform for self-directed learning in the twenty-first century may not be paying attention to the needs of an average learner. Thus, this study has highlighted an urgent need for a well-designed online learning agenda for glaucoma education in the United States.

Furthermore, health care professionals have to be educated in assessing the health literacy of clients and communicating with clients in such a way that they understand their diagnosis, implications of diagnosis, treatment and how to care for themselves. This form of education should be integrated into the curriculum of health professionals. Students should be educated on communicating effectively with patients without using technical terms and ensuring that patients teach back what they had just been told. Students should have an opportunity of using consent and procedure forms during their training.

Likewise, adult educators should teach students to ask questions about test procedures and results. Students should be taught where and how to locate the right information needed to make health decisions and how to determine the accuracy and quality of online information. Also, adult educators should teach students to read charts and accurately interpret them. Although current nursing curriculum in many nursing schools in the United States have

integrated these ideals in teaching many diseases, diseases that affect the eyes have not been a major focus of such efforts.

Recommendations

The findings in this study call for governmental organizations to provide more information about diseases and disorders of the eye that can limit the independence of individuals and their quality of life, which can increase the burden of disease on the health care system. It is recommended that governmental organizations have staff monitoring the news and what people are discussing, “hot topics”, on social media. This will allow appropriate targeting of health information online. The period of news or hot topics are times when individuals are interested in learning about what learners consider important. They seek for information about these topics and acquire knowledge about them. This consequently empowers individuals to make lifestyle changes that prevent the occurrence of diseases and limit the progression of chronic diseases like glaucoma.

As a demographic group, African immigrants constitute a high-risk population for glaucoma. Educational interventions should be targeted at this group to provide information about this symptomless and irreversible disease that steals their sight slowly without their knowledge until it is too late. The significant increase in the scores on the eye-Q test administered before and after exposure to online glaucoma information indicates that if information about glaucoma and other diseases are presented to this population, their knowledge about such diseases will improve.

Adequate knowledge of glaucoma will empower this group of people in the US who are highly educated to manage their lifestyles in such a way as to maintain their sight. Maintenance

of good vision amounts to independence, quality lifestyle and continued contribution to the economic growth of the US and less dependence on the health system. This, on the long run, will reduce the burden on the health care system.

For further work, it is recommended that the accuracy and quality of the online information available on glaucoma be determined. Also, this work could be repeated with a larger sample size of African immigrants in Missouri and all the states of the United States. Changing the sampling method from convenience to a more systematic sampling method would produce data that will enable the generalizability of findings to the general population of African immigrants in the United States.

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AUBURN UNIVERSITY INSTITUTIONAL REVIEW BOARD
REQUEST for MODIFICATION

For Information or help completing this form, contact: **THE OFFICE OF RESEARCH COMPLIANCE (ORC)**
Phone: 334-844-5966 **E-Mail:** IRBAdmin@auburn.edu **Web Address:** http://www.auburn.edu/research /vpr/ohs

In MS Word, click in the white boxes and type your text; double-click checkboxes to check/uncheck.

- **Federal regulations require IRB approval before implementing proposed changes.**
- **Change means any change, in content or form, to the protocol, consent form, or any supportive materials (such as the Investigator's Brochure, questionnaires, surveys, advertisements, etc.). See Item 4 for more examples.**
- **Form must be populated using Adobe Acrobat / Pro 9 or greater standalone program (do not fill out in browser). Hand written forms will not be accepted.**

1. Today's Date	10/10/2019

2. Principal Investigator (PI)

Principal Inves. (title):	Olumayowa A. Odemuyiwa	**Faculty PI (if PI is a student):**	Dr. Maria Witte
Department:	Adult Education	**Department:**	Adult Education
Phone:	334-332-0781	**Phone:**	334-844-0299
AU E-mail:	oao0004@auburn.edu	**AU E-mail:**	wittemm@auburn.edu

Contact person who should receive copies of IRB correspondence (Optional)

Name:		**Department Head:**	Dr. Sherida Downer
Phone:			
AU E-mail:			

3. AU IRB Protocol Identification

3.a. Protocol Number	#19-365
3.b. Protocol Title	Information Gathering to Improve Health Literacy and Understand Glaucoma

3.c. Current Status of Protocol—For active studies, check ONE box at left; provide numbers and dates where applicable

X **Study has not yet begun; no data has been entered collected**

☐ **In progress If YES, number entered**
Adverse events since last review

☐ **Data analysis only**

Approval Dates: From October 1 To October 31

☐ **Funding Agency and Grant Number:** **AU Funding Information:**

☐ **List any other institutions and/or IRBs associated with this project:**

4. Types of Change

Mark all that apply, and describe the changes in item 5

☐ **Change Key Personnel**
Attach CITI forms for new personnel.

☐ **Additional Sites or Change in Sites, including AU classrooms, etc.**
Attach permission forms for new sites.

☐ **Change in methods for data storage/protection or location of data/consent documents**

☐ **Change in project purpose or project questions**

☐ **Change in population or recruitment**
Attach new or revised recruitment materials as needed; both highlighted version & clean copy for IRB approval stamp

☐ **Change in study procedures**
Attach new or revised consent documents as needed; both highlighted version & clean copy for IRB approval stamp

☐ **Change in data collection instruments/forms (surveys, data collection forms)**
Attach new forms as needed; both highlighted version & clean copy for IRB approval stamp

☐ **Other**
(BUAs, DUAs, etc.) Indicate the type of change in the space below, and provide details in Item 5.c. or 5.d. as applicable. Include a copy of all affected documents, with revisions highlighted as applicable.

▶ Change in study completion date

5. Description and Rationale

5.a. For each item marked in Question #4 describe the requested changes to your research protocol, with an explanation and/or rationale for each.
Additional pages may be attached if needed to provide a complete response.

▶ Requesting a change in the time spent on study sites.

▶ The end date for activities at the data collection sites was expected to be October 31, when the protocol was first written in June, 2019. During the protocol revisions, I forgot to change the end date by about 3-4 months, which is the length of time needed for data collection. It is, therefore requested that activities at the data collection sites finish on January 31, 2020 as opposed to the previously proposed October 31, 2019.

5.b. Briefly list (numbered or bulleted) **the activities that have occurred up to this point, particularly those that involved participants.**

▶ None

5.c. Does the change affect participants, such as procedures, risks, costs, benefits, etc.

▶ No

5.d. Identify any changes in the safeguards or precautions that will be used to minimize described risks.

▶

5.e. Attach a copy of <u>all</u> "stamped" IRB-approved documents currently used. (information letters, consents, flyers, etc.

▶ attached

5.f. Attach a copy of all revised documents (high-lighted revised version and clean revised version for the IRB approval stamp).

▶ attached

6. Signatures

Principal Investigator _____  _____

Faculty Advisor PI, if applicable Maria M. Witte _____

AUBURN UNIVERSITY INSTITUTIONAL REVIEW BOARD for RESEARCH INVOLVING HUMAN SUBJECTS

RESEARCH PROTOCOL REVIEW FORM
FULL BOARD or EXPEDITED

For Information or help contact **THE OFFICE OF RESEARCH COMPLIANCE (ORC),** 115 Ramsay Hall, Auburn University
Phone: 334-844-5966 **e-mail:** IRBAdmin@auburn.edu **Web Address:** http://www.auburn.edu/research/vpr/ohs/index.htm

Revised 2.1.2014 **Submit completed form to IRBsubmit@auburn.edu or 115 Ramsay Hall, Auburn University 36849.**

Form must be populated using Adobe Acrobat / Pro 9 or greater standalone program (do not fill out in browser). Hand written forms will not be accepted.

1. PROPOSED START DATE of STUDY: October 1, 2019

PROPOSED REVIEW CATEGORY (Check one): ☐ **FULL BOARD** ☑ **EXPEDITED**

SUBMISSION STATUS (Check one): ☑ **NEW** ☒ **REVISIONS (to address IRB Review Comments)**

2. PROJECT TITLE: Information Gathering to Improve Health Literacy and Understand Glaucoma

3. Olumayowa A. Odemuyiwa	Mrs.	Adult Education	oao0004@tigermail.auburn.edu
PRINCIPAL INVESTIGATOR	**TITLE**	**DEPT**	**AU E-MAIL**
2404 Stratford Chase Pkway, Columbia, MO		3343320781	
MAILING ADDRESS		**PHONE**	**ALTERNATE E-MAIL**

4. FUNDING SUPPORT: ☑ N/A ☐ Internal ☐ External Agency: _____ ☐ Pending ☐ Received

For federal funding, list agency and grant number (if available). _____

5a. List any contractors, sub-contractors, other entities associated with this project:

b. List any other IRBs associated with this project (including Reviewed, Deferred, Determination, etc.):

PROTOCOL PACKET CHECKLIST

All protocols must include the following items:

☑ **Research Protocol Review Form** (All signatures included and all sections completed)
(Examples of appended documents are found on the OHSR website: http://www.auburn.edu/research/vpr/ohs/sample.htm)

☑ **CITI Training Certificates** for all Key Personnel.

☑ **Consent Form or Information Letter** and any Releases (audio, video or photo) that the participant will sign.

☑ **Appendix A**, "Reference List"

☑ **Appendix B** if e-mails, flyers, advertisements, generalized announcements or scripts, etc., are used to recruit participants.

☑ **Appendix C** if data collection sheets, surveys, tests, other recording instruments, interview scripts, etc. will be used for data collection. Be sure to attach them in the order in which they are listed in # 13c.

☐ **Appendix D** if you will be using a debriefing form or include emergency plans/procedures and medical referral lists (A referral list may be attached to the consent document).

☑ **Appendix E** if research is being conducted at sites other than Auburn University or in cooperation with other entities. A **permission letter** from the site / program director must be included indicating their cooperation or involvement in the project. NOTE: If the proposed research is a multi-site project, involving investigators or participants at other academic institutions, hospitals or private research organizations, a letter of **IRB approval** from each entity is required prior to initiating the project.

☐ **Appendix F** - Written evidence of acceptance by the host county if research is conducted outside the United States.

FOR ORC OFFICE USE ONLY

DATE RECEIVED IN ORC: _____ **by** _____ **PROTOCOL #** _____
DATE OF IRB REVIEW: _____ **by** _____ **APPROVAL CATEGORY:** _____
DATE OF IRB APPROVAL: _____ **by** _____ **INTERVAL FOR CONTINUING REVIEW:** _____
COMMENTS:

6. GENERAL RESEARCH PROJECT CHARACTERISTICS

6A. Research Methodology

Please check all descriptors that best apply to the research methodology.

Data Source(s): ☑ New Data ☑ Existing Data

Will recorded data directly or indirectly identify participants?
☐ Yes ☑ No

Data collection will involve the use of:

- Educational Tests (cognitive diagnostic, aptitude, etc.)
- Interview
- Observation
- Location or Tracking Measures
- Physical / Physiological Measures or Specimens (see Section 6E.)
- ✓ Surveys / Questionnaires
- ✓ Internet / Electronic
- Audio
- Video
- Photos
- Digital images
- Private records or files

Other: Publicly available data

6B. Participant Information

Please check all descriptors that apply to the target population.
☑ Males ☑ Females ☐ AU students

Vulnerable Populations
☐ Pregnant Women/Fetuses ☐ Prisoners ☐ Institutionalized
☐ Children and/or Adolescents (under age 19 in AL)

Persons with:
☐ Economic Disadvantages ☐ Physical Disabilities
☐ Educational Disadvantages ☐ Intellectual Disabilities

Do you plan to compensate your participants? ☐ Yes ☑ No

6C. Risks to Participants

Please identify all risks that participants might encounter in this research.

☐ Breach of Confidentiality* ☐ Coercion
☐ Deception ☐ Physical
☐ Psychological ☐ Social
☑ None
☐ Other:

*Note that if the investigator is using or accessing confidential or identifiable data, breach of confidentiality is always a risk.

6D. Corresponding Approval/Oversight

- **Do you need IBC Approval for this study?**
  ☐ Yes ☐ No

  If yes, BUA #_____ Expiration date _____

- **Do you need IACUC Approval for this study?**
  ☐ Yes ☐ No

  If yes, PRN #_____ Expiration date _____

- **Does this study involve the Auburn University MRI Center?**
  ☐ Yes ☐ No

  Which MRI(s) will be used for this project? (Check all that apply)
  ☐ 3T ☐ 7T

  Does any portion of this project require review by the MRI Safety Advisory Council?
  ☐ Yes ☐ No

  Signature of MRI Center Representative: _____
  Required for all projects involving the AU MRI Center

  Appropriate MRI Center Representatives:
  Dr. Thomas S. Denney, Director AU MRI Center
  Dr. Ron Beyers, MR Safety Officer

A. PRINCIPAL INVESTIGATOR'S ASSSURANCES

1. I certify that all information provided in this application is complete and correct.
2. I understand that, as Principal Investigator, I have ultimate responsibility for the conduct of this study, the ethical performance this project, the protection of the rights and welfare of human subjects, and strict adherence to any stipulations imposed by the Auburn University IRB.
3. I certify that all individuals involved with the conduct of this project are qualified to carry out their specified roles and responsibilities and are in compliance with Auburn University policies regarding the collection and analysis of the research data.
4. I agree to comply with all Auburn policies and procedures, as well as with all applicable federal, state, and local laws regarding the protection of human subjects, including, but not limited to the following:
    a. Conducting the project by qualified personnel according to the approved protocol
    b. Implementing no changes in the approved protocol or consent form without prior approval from the Office of Research Compliance
    c. Obtaining the legally effective informed consent from each participant or their legally responsible representative prior to their participation in this project using only the currently approved, stamped consent form
    d. Promptly reporting significant adverse events and/or effects to the Office of Research Compliance in writing within 5 working days of the occurrence.
5. If I will be unavailable to direct this research personally, I will arrange for a co-investigator to assume direct responsibility in my absence. This person has been named as co-investigator in this application, or I will advise ORC, by letter, in advance of such arrangements.
6. I agree to conduct this study only during the period approved by the Auburn University IRB.
7. I will prepare and submit a renewal request and supply all supporting documents to the Office of Research Compliance before the approval period has expired if it is necessary to continue the research project beyond the time period approved by the Auburn University IRB.
8. I will prepare and submit a final report upon completion of this research project.

My signature indicates that I have read, understand and agree to conduct this research project in accordance with the assurances listed above.

Olumayowa A. Odemuyiwa		06/09/2019
Printed name of Principal Investigator	**Principal Investigator's Signature**	**Date**

B. FACULTY ADVISOR/SPONSOR'S ASSURANCES

1. I have read the protocol submitted for this project for content, clarity, and methodology.
2. By my signature as faculty advisor/sponsor on this research application, I certify that the student or guest investigator is knowledgeable about the regulations and policies governing research with human subjects and has sufficient training and experience to conduct this particular study in accord with the approved protocol.
3. I agree to meet with the investigator on a regular basis to monitor study progress. Should problems arise during the course of the study, I agree to be available, personally, to supervise the investigator in solving them.
4. I assure that the investigator will promptly report significant incidents and/or adverse events and/or effects to the ORC in writing within 5 working days of the occurrence.
5. If I will be unavailable, I will arrange for an alternate faculty sponsor to assume responsibility during my absence, and I will advise the ORC by letter of such arrangements. If the investigator is unable to fulfill requirements for submission of renewals, modifications or the final report, I will assume that responsibility.

Maria Martinez Witte	Maria M. Witte	June 26, 2019
Printed name of Faculty Advisor / Sponsor	**Faculty Advisor's Signature**	**Date**

C. DEPARTMENT HEAD'S ASSSURANCE

By my signature as department head, I certify that I will cooperate with the administration in the application and enforcement of all Auburn University policies and procedures, as well as all applicable federal, state, and local laws regarding the protection and ethical treatment of human participants by researchers in my department.

	Sherida Downer Digitally signed by Sherida Downer Date: 2019.08.20 12:21:25 -05'00'	
Printed name of Department Head	**Department Head's Signature**	**Date**

8. **PROJECT OVERVIEW: Prepare an abstract that includes:**
(**350** word maximum, in language understandable to someone who is not familiar with your area of study):

a) **A summary of relevant research findings leading to this research proposal:**
(Cite sources; include a "Reference List" as Appendix A.)
b) **A brief description of the methodology, including design, population, and variables of interest**

A quarter of American adults are functionally illiterate, making health information difficult for them to understand (Parker, 2000). This poses a self-management risk to individuals with one chronic disease or the other (IOM, 2013; Parker, 2000). However, the advent of the internet has made health information easily accessible to the public. The impact of public-sourced information on the overall health literacy (HL) of the population is still poorly understood (IOM, 2013). A better understanding of the interaction of users with the information obtained from the internet environment will help to structure health-information dissemination in a way that can significantly improve HL. Researchers have investigated the type and accuracy of online health information (Berland, et al., 2001; Benotsch, Kalichman & Weinhardt, 2004). Also, the flow, and the frequency of flow of information have been studied (Hanna & Hanna, 2018; Hassid, et al., 2017; Harsha, Schmitt, & Stavropoulos, 2014). However, there is a paucity of information in the literature on how the internet is used as an online educational tool to understand glaucoma. This chronic eye condition is common amongst individuals of African ancestry and is the leading cause of blindness in the United States. If discussed, the accuracy of the information shared is questionable. Thus, it is necessary to conduct an evaluation of the information on the internet about glaucoma to identify possible gaps between who is seeking glaucoma information and what they want to know about the disease.
Methodology:
• Use google trend to access data on glaucoma information search from 2007-2017 and over the past 12 months.
• Use the patient ambulatory discharge database and the National Ambulatory Medical Care Survey (NAMCS) database from 2007 to 2017 to determine prescriptions of medications specifically used in treating glaucoma.
• Use the National Health Interview Survey (NHIS) data to access the individual variables that will predispose an individual to search for glaucoma information
• Assess HL about glaucoma using the Eye-Q test (NEHEP) before and after exposing individuals to glaucoma online health information.
• Assess electronic HL using eHEALS, an 8-item electronic HL survey.

9. **PURPOSE.**
a. **Clearly state the purpose of this project and all research questions, or aims.**

Identify the individual and population characteristics of those who seek information about glaucoma via Google. Identify the learning needs of information seekers (IS) by evaluating the type of information they seek online. Determine the value of the information obtained as a glaucoma educational tool. Evaluate the ehealth literacy of African immigrants living in Missouri and determine how it affects their knowledge and online ISB about glaucoma Research Questions: • What type of information about glaucoma do individuals search online?• What events trigger an increase in search for information on glaucoma? • What is the health educational value of online information obtained from google searches on glaucoma?• Is there a relationship between the search for glaucoma information and the diagnosis of glaucoma or prescription of glaucoma medication? • What are the factors that will predict that an individual will search for health information on glaucoma online?• What factors will predict health literacy and knowledge about glaucoma in African immigrants to the United States? • Does health literacy level among African immigrants to the United States predict their knowledge about glaucoma?

b. **How will the results of this project be used? (e.g., Presentation? Publication? Thesis? Dissertation?)**

The results of this project will be used in writing a PhD dissertation and findings will be published in peer-reviewed journals.

10. **KEY PERSONNEL.** Describe responsibilities. Include information on research training or certifications related to this project. **CITI is required. Be as specific as possible.** (Include additional personnel in an attachment.) *All key personnel must attach CITI certificates of completion.*

Principle Investigator Olumayowa A. Odemuyiwa **Title:** Mrs. **E-mail address** oao0004@tigermail.auburn.edu

Dept / Affiliation: Adult Education

Roles / Responsibilities:

Coordination of the study, data collection and analysis ***recruitment of participants, including receiving the consent from participants***

Individual: Dr. Maria Witte **Title:** *Dr.* **E-mail address** *wittem@auburn.edu*

Dept / Affiliation: **Adult Education**

Roles / Responsibilities:

Advisor

Individual: _____ **Title:** _____ **E-mail address** _____

Dept / Affiliation: _____

Roles / Responsibilities:

Individual: _____ **Title:** _____ **E-mail address** _____

Dept / Affiliation: _____

Roles / Responsibilities:

Individual: _____ **Title:** _____ **E-mail address** _____

Dept / Affiliation: _____

Roles / Responsibilities:

Individual: _____ **Title:** _____ **E-mail address** _____

Dept / Affiliation: _____

Roles / Responsibilities:

11. **LOCATION OF RESEARCH. List all locations where data collection will take place.** (School systems, organizations, businesses, buildings and room numbers, servers for web surveys, etc.) **Be as specific as possible. Attach permission letters in** Appendix E.
(See sample letters at http://www.auburn.edu/research/vpr/ohs/sample.htm)

Data collection will take place at places where African immigrants worship more often. The sites of worship chosen are the Redeemed Christian Church of God in Columbia, St. Louis and Kansas City, and Christ's Chapel in Columbia.

12. PARTICIPANTS.

a. **Describe the participant population you have chosen for this project including inclusion or exclusion criteria for participant selection.**

☑ **Check here if using existing data, describe the population from whom data was collected, & include the # of data files.**

The National Health Interview Survey (NHIS): Data were collected from household members who were 17 years and older. Data collected between 2007 and 2017 will be used.
The National Ambulatory Medical Care Survey (NAMCS) database : Database include national data collected from individuals who visited the emergency departments, outpatient clinics, and ambulatory surgery locations and short hospital stays. Data did not include institutionalized individuals. Data files from 2007 to 2017 will be used. Samples are nationally representative of healthcare use in hospitals, clinician offices and longterm care facilities across the nation,

The participant population chosen for this study will be recruited from the Redeemed Christian Church of God (a lot of African immigrants go to this church) in three cities namely Columbia, Kansas City and St. Louis, Missouri, USA.
The participants will be adult men and women above the age of 18, who are immigrants from Africa.
Exclusion criteria: Individuals less than 18 years.

b. **Describe, step-by-step, in layman's terms, all procedures you will use to recruit participants.** *Include in Appendix B a copy of all e-mails, flyers, advertisements, recruiting scripts, invitations, etc., that will be used to invite people to participate. (See sample documents at http://www.auburn.edu/research/vpr/ohs/sample.htm.)*

A Pastor of the Redeemed church of God in Missouri was notified of the study. He gave his consent to have the study in his church. In addition, this pastor linked me with the pastors of the other churches. These pastors have been informed of the study and site authorization obtained. Each pastor will give me a time that is convenient to meet with his congregation during a church service. The congregation will be invited to wait after the church service to meet with them to inform them of the study.
The recruitment script will be read to the church members. The members that agree to participate will be given the consent form to sign. The individuals that give their consent to participate are the individuals that will be included in the study.

c. **What is the minimum number of participants you need to validate the study?** 250

How many participants do you expect to recruit? 250

Is there a limit on the number of participants you will include in the study? ☑ **No** ☐ **Yes – the # is** _____

d. **Describe the type, amount and method of compensation and/or incentives for participants.**

(If no compensation will be given, check here: ☑)

Select the type of compensation: ☐ Monetary ☐ Incentives
- ☐ Raffle or Drawing incentive (Include the chances of winning.)
- ☐ Extra Credit (State the value)
- ☐ Other

Description:

Snacks will be provided during the time of participation in the study.

13. PROJECT DESIGN & METHODS.

a. **Describe, step-by-step, all procedures and methods that will be used to consent participants. If a waiver is being requested, check each waiver you are requesting, describe how the project meets the criteria for the waiver.**

- [X] **Waiver of Consent (including using existing data)**
- [ ] **Waiver of Documentation of Consent (use of Information Letter)**
- [ ] **Waiver of Parental Permission (for college students)**

Participants will first be recruited by reading the recruitment script in their hearing. Once they agree to participate, the consent forms will be given to obtain participants' signatures to indicate their awareness of the study, its benefits and possible risks.

b. **Describe the research design and methods you will use to address your purpose. Include a clear description of when, where and how you will collect all data for this project.** Include specific information about the participants' time and effort commitment. (*NOTE: Use language that would be understandable to someone who is not familiar with your area of study. Without a complete description of all procedures, the Auburn University IRB will not be able to review this protocol. If additional space is needed for this section, save the information as a .PDF file and insert after page 7 of this form.*)

See attached document.

13. **PROJECT DESIGN & METHODS.** *Continued*

c. **List all data collection instruments used in this project, in the order they appear in** Appendix C.
(e.g., surveys and questionnaires **in the format that will be presented to participants**, educational tests, data collection sheets, interview questions, audio/video taping methods etc.)

Demographic survey
Eye-Q Survey
eHEALS

d. **Data analysis: Explain how the data will be analyzed.**

A trend of searched volumes will be described. Population characteristics will be presented using maps, graphs and charts. Comparison will be done using Chi-square, t-test and binary linear regression. Computational text analysis using R. Pearson correlation coefficient will be used to assess correlations between google trends data and the NAMCS data output.Logistic regression to predict characteristics for online glaucoma information seeking

14. **RISKS & DISCOMFORTS: List and describe all of the risks that participants might encounter in this research.** ***If you are using deception in this study, please justify the use of deception and be sure to attach a copy of the debriefing form you plan to use in Appendix D.*** *(Examples of possible risks are in section #6D on page 2)*

The risks associated with participating in this project are possible breach of confidentiality and the feelings that participants have to participate because they are members of the church in which the study will be carried out.

15. **PRECAUTIONS.** Identify and describe all precautions you have taken to eliminate or reduce risks as listed in #14. If the participants can be classified as a "vulnerable" population, please describe additional safeguards that you will use to assure the ethical treatment of these individuals. ***Provide a copy of any emergency plans/procedures and medical referral lists in*** *Appendix D.* ***(Samples can be found online at http://www.auburn.edu/research/vpr/ohs/sample.htm#precautions)***

To eliminate or minimize risks or discomfort associated with this study, we will ensure confidentiality of participants' information. Data analysis will be carried out in such a way that no information that could identify the participants will be used. Participation in the project is completely voluntary; individuals can withdraw at any time and withdrawal will not affect participants as members of the church.

If using the Internet or other electronic means to collect data, what confidentiality or security precautions are in place to protect (or not collect) identifiable data? Include protections used during both the collection and transfer of data.

The data collected via Google trend does not have any identifiable information. Likewise, data from NHIS and the NAMCS are deidentified.

16. **BENEFITS.**

a. **List all realistic direct benefits participants can expect by participating in this specific study.**
(Do not include "compensation" listed in #12d.) Check here if there are no direct benefits to participants. ☐

The participants can expect to be aware of and receive information on glaucoma, a chronic eye condition that is common among individuals of African ancestry. In addition, they can expect to receive information on how to access, obtain and use health information in meeting their healthcare needs. The participation of individuals in the study will further empower them in their navigation of the healthcare system, improve their health, reduce morbidity, hospital admissions and readmissions, blindness related to glaucoma and healthcare spending.

b. **List all realistic benefits for the general population that may be generated from this study.**

As a result of this study, individuals with glaucoma will be more knowledgeable of where to source for adequate and quality information about glaucoma on the internet. Individuals with chronic conditions sourcing for information on the internet will be more cautious with their use of the information obtained. They will learn to check information they obtain with healthcare providers before using them. This study will enable individuals with chronic conditions to be more compliant with their treatment regimen. They will be empowered to care for themselves and manage their various diseases more effectively. This will reduce morbidity, mortality and healthcare spending.

17. PROTECTION OF DATA.

a. **Data are collected:**

☑ **Anonymously with no direct or indirect coding, link, or awareness of who participated in the study (Skip to e)**

☑ **Confidentially, but without a link of participant's data to any identifying information (collected as "confidential" but recorded and analyzed as "anonymous") (Skip to e)**

☐ **Confidentially with collection and protection of linkages to identifiable information**

b. **If data are collected with identifiers or as coded or linked to identifying information, describe the identifiers collected and how they are linked to the participant's data.**

Identifiers that will be collected are signed consent forms. These will, however, not be linked to the participants' information in any way.

c. **Justify your need to code participants' data or link the data with identifying information.**

The participants do not need to be identified, but a de-identifier code will be assigned. The participants will be asked to complete the survey using their middle initial followed by the last four digits of their phone numbers. These codes will be provided by the participants each time they complete the survey.

d. **Describe how and where identifying data and/or code lists will be stored.** (Building, room number?) **Describe how the location where data is stored will be secured in your absence. For electronic data, describe security. If applicable, state specifically where any IRB-approved and participant-signed consent documents will be kept on campus for 3 years after the study ends.**

IRB- approved and participant signed consent forms will be stored in faculty advisor's office.

e. **Describe how and where the data will be stored** (e.g., hard copy, audio cassette, electronic data, etc.)**, and how the location where data is stored is separated from identifying data and will be secured in your absence. For electronic data, describe security**

Data will be stored on a flash drive. The hard copy will be stored with faculty advisor.

The jump drive and laptop that will be used will be encrypted using bitlocker. Files will be password protected. The consents signed by participants will be put in a sealed envelope before securing it in a bag, which will later be taken by the student to the Faculty advisor.

f. **Who will have access to participants' data?**
(*The faculty advisor should have full access and be able to produce the data in the case of a federal or institutional audit.*)

Faculty advisor will have access to data collected.

g. **When is the latest date that identifying information or links will be retained and how will that information or links be destroyed?**
(Check here if only anonymous data will be retained ☑)

Identifying information will be retained for a period of 3 years.

13b

Research Matrix: Research questions and proposed methods to use

Research Questions	Proposed method	Analysis
• What type of glaucoma information do individuals search online? • What events trigger an increase in search for information on glaucoma? • What is the health educational value of online information obtained from google searches on glaucoma?	• Use Google Trends, an online database of all google searches over time, to determine the frequency of search for information on glaucoma over the internet. • Geographical origin of searches within the United States will be identified • Publically available population data will be obtained from the websites of the United States Census Bureau • Trigger events will be identified. Information obtained during spike in searches will be retrieved (the first five websites yielded on Google during a peak glaucoma search). • Subject information retrieved to content analysis and compare findings to the teaching material on glaucoma provided on the National Eye Institute (NEI) website. • Do content analysis manually and computationally using R software	• Search volume numbers over time will be analyzed and a trend will be described • Population characteristics of geographical areas from where searches originated will be presented using maps, graphs and charts. Comparison will be done using Chi-square, t-test and binary linear regression • Data will be analyzed using SPSS.
• Is there a relationship between the search for glaucoma information and the diagnosis of glaucoma or prescription of glaucoma medication?	• Use the patient ambulatory discharge database and the National Ambulatory Medical Care Survey (NAMCS) database (over a period of 10 years from 2007 to 2017) determine prescriptions of medications specifically used in treating glaucoma. • Carry out a correlation analysis of the data obtained from google trend and the prescription rate for medications used specifically for glaucoma. The census data from different regions of the United States from where searches were done will also be extracted.	• Pearson correlation coefficient will be used to assess correlations between google trends data and the NAMCS data output.

• What are the factors that will predict that an individual will search for health information on glaucoma online?	• Use the National Health Interview Survey (NHIS) data to access the individual variables that will predispose an individual to search for glaucoma information •	• Logistic regression analysis will be used to predict that an individual will search for glaucoma information online
• What factors will predict health literacy and knowledge about glaucoma in African immigrants to the United States? • Does health literacy level among African immigrants to the United States predict their knowledge about glaucoma? • Locations: Saint Louis, Columbia, and Kansas City	• Assess health literacy about glaucoma using the Eye-Q test (NEHEP) before and after exposing individuals to glaucoma online health information. • Participants will also take the eHEALS questionnaire, which is an 8-item electronic health literacy survey.	• T test to compare results in a group. • One-way ANOVA to compare the results of 3 groups (from 3 cities).

Proposed Instrumentation

Google Trends: This is an online database compiles the results of every internet search done since 2004 using the Google search engine. Results of a search using a given term are expressed as relative search volume (RSV). This scaled value expresses the volume of search during the week, month or year of interest relative to the search volume during the week, month or year that has the highest number of searches for that term. The week with the highest search volume is assigned an RSV of 100 while the other weeks have values that range from 0 to 99. A plot made using this value can be overlaid with specific news events to determine possible trigger events for changes in trend. Google Trend data has emerged as an effective method to measure user behavior and predict events of public health importance e.g. influenza outbreaks (Google,2018; Hassid, et al. 2017). In the present study, Google Trends will be used to access data on glaucoma

information search for a period of 10 years (2007-2017) and over the past 12 months. This will give information on the relative search volumes for different states (regions) for a period of 10 years. Focus will be on weeks where spikes in searches for glaucoma information are present to identify the trigger events. A Google search will then be done to identify the specific events during this period that relates to glaucoma. The information presented from the top 10 pages will be subjected to content analysis to evaluate their educational value about glaucoma in comparison with the official online educational materials provided by the National Eye Institute.

The National Eye Health Education Program (NEHEP) Eye-Q test: This is a 10-item true or false survey questions used to assess glaucoma knowledge. This test is publicly available. The Cronbach's coefficient for this test was moderate at 0.592 (Rao et al, 2016). Another test with a higher coefficient value of 0.88 indicating higher internal consistency and validity is a 49 item survey questions, which is a combination of four glaucoma survey questions. The NEHEP knowledge assessment was previously given high ranking by glaucoma clinicians as most useful for clinical practice. Rao et al (2016) however, suggested from their study that it lacks internal consistency but has a reasonable level of difficulty.

eHEALS: ehealth literacy scale is a measure of self-perceived health literacy. It will be used to measure participants' level of health literacy. The eHEALS is an 8-item electronic health literacy survey. It uses a 5-point Likert scale to answer questions with response options ranging from "strongly agree" to "strongly disagree". Cronbach's alpha, a measure of internal consistency is .88. Item-scale correlations between items ranged from .51 to .76.

AUBURN UNIVERSITY
COLLEGE OF EDUCATION

EDUCATIONAL FOUNDATIONS, LEADERSHIP AND TECHNOLOGY

INFORMED CONSENT

To participate in a research study on
"Information Gathering to Improve Health Literacy and Understand Glaucoma"

You are invited to participate in a research study on information gathering to improve health literacy and understand glaucoma. The project is being conducted by Nike Odemuyiwa, a PhD student at Auburn University under the direction of Dr. Maria Witte of the College of Education.

What will be involved if you participate? As a participant, you will complete three questionnaires. One seeks information about you, the participant, while the other two assess your electronic health literacy and your understanding of glaucoma. After your completion of these questionnaires, you will be exposed to online glaucoma information where you will learn about glaucoma. The survey that assesses your understanding of glaucoma will be given to you again to complete after you have accessed the information.

Are there any risks or discomforts? The risks associated with participating in this project are possible breach of confidentiality and the feelings that you have to participate because you are a member of this church. To minimize these risks, we will ensure that your information is treated confidentially and for the purpose of data analysis. No information that could identify you will be collected in this study. Participation in the project is completely voluntary and will not affect you as a member of this church.

Are there any benefits to yourself or others? The information gathered from this study will be used to determine the health literacy of African immigrants in the United States (US), their health literacy about glaucoma and how best to help this population to access, obtain, and use health information and services to meet their health needs. In addition, health professionals will be aware of the limitations faced by this immigrant group in the US and develop strategies to empower them in meeting their health needs.

Will you receive compensation for participating? No, there is no compensation for participating.

Are there any costs? No, there are no costs to participate.

If you change your mind about participating: You can withdraw at any time during the project. Your participation is voluntary. If you choose to withdraw, your data will be deleted as long as it is identifiable. Your decision about whether or not to participate or to stop participating will not jeopardize your future relations with Auburn University or your membership at this church.

4036 Haley Center, Auburn, AL 36849-5221; Telephone: 334-844-4460: Fax: 334-844-3072

www.auburn.edu

Your privacy will be protected. Any information obtained in connection with this study will remain confidential. Information obtained through your participation may be used in a presentation used to fulfill an educational requirement. It may also be used in a publication to increase knowledge. However, no names or any participant-identifying information will be used.

If you have questions about this project, please ask them now, or contact my faculty advisor Dr. Maria Witte, at wittem@auburn.edu. A copy of this document will be given to you to keep.

If you have questions about your rights as a research participant, you may contact the Auburn University Office of Human Subjects Research by phone (334)-844-5966 or e-mail at hsubjec@auburn.edu

HAVING READ THE INFORMATION PROVIDED, YOU MUST DECIDE WHETHER YOU WISH TO PARTICIPATE IN THIS RESEARCH STUDY. YOUR SIGNATURE INDICATES YOUR WILLINGNESS TO PARTICIPATE.

_____	_____
Participant's signature	Investigator obtaining consent
Date_____	Date_____
_____	_____
Printed Name	Printed Name

June 07/2019

Auburn University Institutional Review Board
c/o Office of Human Subjects
115 Ramsey Hall
Auburn University, AL 36849

Please note that "Nike Odemuyiwa", Auburn University College of Education Graduate Student, has the permission of the pastor of the Redeemed Christian Church of God to conduct a study at our church entitled "Information Gathering to Improve Health Literacy and Understand Glaucoma".

"Nike Odemuyiwa" will provide participating members at our church with a consent form addressing all aspects of the project and they will be asked to sign the consent form and complete a self-assessment questionnaire on glaucoma and allow their assessment results to be used in the project. In addition, she will give them eHEALS questionnaire to assess members' health literacy, after which she will expose them to online information on glaucoma and then re-administer the glaucoma self-assessment. Nike's on-site activities will be finished no later than " January 31, 2020".

Nike has agreed not to include church members who are not willing to participate in this project. She has also agreed to provide a copy of the Auburn University IRB-approved, stamped consent document before she recruits church members. In addition, she has agreed to share the results of the study with the church.

If there are any questions, please contact me.

Signed, Fami Ogungbade

Pastor, Redeemed Church of God Columbia

Glaucoma can take your sight away.

Keep Vision in Your Future.

Take This Eye-Q Test To See How Much You Know About Glaucoma

Millions of Americans are at risk for vision loss from glaucoma, a leading cause of blindness in the United States. Are you one of them? If you are, do you know how to reduce your risk of blindness? To determine how high your Eye-Q is, answer the following questions about glaucoma.

	True	False	Not Sure
1. Glaucoma is more common in African Americans than in Whites.			
2. Glaucoma tends to run in families.			
3. A person can have glaucoma and not know it.			
4. People over age 60 are more likely to get glaucoma.			
5. Eye pain is often a symptom of glaucoma.			
6. Glaucoma can be controlled.			
7. Glaucoma is caused by increased eye pressure.			
8. Vision lost from glaucoma can be restored.			
9. A complete glaucoma exam consists only of measuring eye pressure.			
10. People at risk for glaucoma should have an eye examination through dilated pupils.			

To see if you have a perfect Eye-Q score, read all the answers on the back. If you got 9 or 10 right, congratulations. You know a lot about glaucoma. If you missed some, review the answers so you can share your knowledge with your family and friends.

National Eye Institute
NATIONAL INSTITUTES OF HEALTH
National Eye Health Education Program
NEHEP

Answers

1. **True.** In a study funded by the National Eye Institute, researchers at The Johns Hopkins University reported that glaucoma is three to four times more likely to occur in African Americans than in Whites. In addition, glaucoma is six times more likely to cause blindness in African Americans than in Whites.
2. **True.** Although glaucoma tends to run in families, a hereditary basis has not been established. If someone in your immediate family has glaucoma, you should have a comprehensive dilated eye examination every one to two years.
3. **True.** The early stages of open-angle glaucoma, the most common form, usually have no warning signs. However, as the disease progresses, a person with glaucoma may notice his or her side vision gradually failing.
4. **True.** Everyone over age 60 is at an increased risk for glaucoma, especially Mexican Americans. Other groups at increased risk are African Americans over age 40 and people with a family history of glaucoma. Children and babies can also develop glaucoma.
5. **False.** People with glaucoma usually do not experience pain from the disease.
6. **True.** Although glaucoma cannot be cured, it can usually be controlled by eye drops or pills, conventional surgery, or laser surgery. Sometimes eye care professionals will recommend a combination of surgery and medication.
7. **False.** Increased eye pressure means you are at increased risk for glaucoma, but does not mean you have the disease. A person has glaucoma only if the optic nerve is damaged. If you have increased eye pressure but no damage to the optic nerve, you do not have glaucoma. Follow the advice of your doctor.
8. **False.** Vision loss from glaucoma is permanent. However, with early detection and treatment, the progression of vision loss can be slowed or halted, and the risk of blindness reduced.
9. **False.** A measurement of eye pressure by tonometry, though an important part of a comprehensive eye exam, is, by itself, not sufficient for the detection of glaucoma. Glaucoma is detected most often during an eye examination through dilated pupils. Drops are put into the eyes during the exam to enlarge the pupils, which allows the eye care professional to see more of the inside of the eye to check for signs of glaucoma. When indicated, a visual field test should also be performed.
10. **True.** An eye examination through dilated pupils is the best way to diagnose glaucoma. Individuals at increased risk for the disease should have their eyes examined through dilated pupils every one to two years by an eye care professional.

Get your eyes examined.
Don’t lose sight of glaucoma.
http://www.nei.nih.gov/glaucoma

Appendix A

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RECRUITMENT SCRIPT (verbal, in person)

My name is **Nike Odemuyiwa**, a PhD *student* from the College of Education at Auburn University. I would like to invite you to participate in a research study to evaluate if online information access improves health literacy and understanding about glaucoma. You may participate if you are over 18 years of age. Please do not participate if you are less than 18.

As a participant, you will be asked to complete a survey that asks questions about yourself and two questionnaires that assess your electronic health literacy and your understanding of glaucoma. After completing these questionnaires, you will have access to online glaucoma information where you will learn about glaucoma. The survey that assesses your understanding of glaucoma will be given to you again to complete after you have reviewed the information. The study will take about 45 minutes of your time.

If you participate in this project, you will have a better understanding of glaucoma, how to detect and treat it early before it is too late. There are also risks associated with participating in this project, which are the possible breach of confidentiality and the feeling that you have to participate because you are a member of this church. To minimize these risks, we will ensure that your information is treated confidentially and for the purpose of data analysis, no information that could identify you will be used in any way. In addition to exposing you to the online available information on glaucoma, fact sheets about glaucoma will be available for you to take home.

If you would like to participate in this research study, you will receive a consent form that explains the study in more detail. You will sign the consent form to indicate your agreement to participate in this study.

Do you have any questions now? If you have questions later, please contact me at 334-332-0781 or you may contact my advisor, Dr. Maria Witte at 334-844-0299.

Thank you,

Appendix B

Age: What is your age?

A. 18-24 years old
B. 25-34 years old
C. 35-44 years old
D. 45-54 years old
E. 55-64 years old
F. 65-74 years old
G. 75 years or older

Education: What is the highest degree or level of school you have completed? *If currently enrolled, highest degree received.*

A. No schooling completed
B. Kindergarten to 8th grade
C. Some high school, no diploma
D. High school graduate, diploma or the equivalent (for example: GED)
E. Some college credit, no degree
F. Trade/technical/vocational training
G. Associate degree
H. Bachelor's degree
I. Master's degree
J. Professional degree
K. Doctorate degree

Gender: What is your gender?
A. Female
B. Male
C Other (specify)

Marital Status: What is your marital status?

A. Single, never married
B. Married or domestic partnership
C. Widowed
D. Divorced
E. Separated

Employment Status: Are you currently…?

A. Employed for wages
B. Self-employed
C. Out of work and looking for work
D. Out of work but not currently looking for work

E. A homemaker
F. A student
G. Military
H. Retired
I. Disabled, not able to work

Household Income

What is your annual household income (husband and wife, if married)?

A. Less than 10,000
B. 10000 -30000
C. 31000 – 50000
D. 51000 – 70000
E. 71000 – 90000
F. 91000 – 110000
G. >110000

Do you have access to a computer?

A. Yes
B. No

How do you access the internet?

A. Using a personal desktop computer
B. Using a work desktop computer
C. Using a personal laptop computer
D. Using a mobile device
E. Using library or other public computers

How often do you search for information on the internet?

A. Daily
B. 3-4 times a week
C. 1-2 times a week
D. Every other week
E. 2-3 times a month
F. Monthly
G. Not at all

How often do you search the internet for information relating to your own health issues?

A. Daily
B. 3-4 times a week
C. 1-2 times a week

D. Every other week
E 2-3 times a month
F. Monthly
G. Not at all

How often do you search for other health related issues on the internet

A. Daily

B. 3-4 times a week
C. 1-2 times a week
D. Every other week
E. 2-3 times a month
F. Monthly
G. Not at all

Length of residence in the United States

A. Born in the U.S.
B. In US for < 1 year
C. In U.S. for 1-5 years,
D. In U.S. for 6-10 years,
E. In U.S. for more than 10 years.

Do you have health insurance?

A. Yes
B. No

Do you have a family physician?

A. Yes
B. No
C. I do not need one

When was the last time you visited a healthcare provider?

A. Last month
B. Last 3 months
C. Last 12 months
D. Greater than 12 months ago

How often do you visit a healthcare provider?

A. Once a year for physical assessment
B. Only when I am sick
C. I have been healthy, I don't need one
D. Never seen one since in the US

Which of the following activities did you carry out on the internet in the last 12 months?

A. Looked up health information on internet
B. Used chat groups to learn about health topics
C. Refilled prescription on internet
D. Scheduled medical appointment on internet
E. Communicated with health care provider by email

Which of the following social media platforms are you familiar with?

A. Facebook
B. Instagram
C. Twitter
D. Reddit
E. Quora
F. Youtube
G. Pinterest
H. Snapchat

Appendix C: eHealth Literacy Scale

I would like to ask you for your opinion and about your experience using the Internet for health information. For each statement, tell me which response best reflects your opinion and experience *right now*.

1. How **useful** do you feel the Internet is in helping you in making decisions about your health?

□1	□2	□3	□4	□5
Not useful at all	Not useful	Unsure	Useful	Very Useful

2. How **important** is it for you to be able to access health resources on the Internet?

□1	□2	□3	□4	□5
Not important at all	Not important	Unsure	Important	Very important

3. I know **what** health resources are available on the Internet

1) □ Strongly Disagree
2) □ Disagree
3) □ Undecided
4) □ Agree
5) □ Strongly Agree

4. I know **where** to find helpful health resources on the Internet

1) □ Strongly Disagree
2) □ Disagree
3) □ Undecided
4) □ Agree
5) □ Strongly Agree

5. I know **how** to find helpful health resources on the Internet

1) □ Strongly Disagree
2) □ Disagree
3) □ Undecided
4) □ Agree
5) □ Strongly Agree

6. I know **how to use** the Internet to answer my questions about health

1) □ Strongly Disagree
2) □ Disagree
3) □ Undecided
4) □ Agree
5) □ Strongly Agree

7. I know how to use **the health information** I find on the Internet to help me

1) □ Strongly Disagree
2) □ Disagree
3) □ Undecided
4) □ Agree
5) □ Strongly Agree

8. I have the skills I need to **evaluate** the health resources I find on the Internet

1) □ Strongly Disagree
2) □ Disagree
3) □ Undecided
4) □ Agree
5) □ Strongly Agree

9. I can tell **high quality** health resources from **low quality** health resources on the Internet

1) □ Strongly Disagree
2) □ Disagree
3) □ Undecided
4) □ Agree
5) □ Strongly Agree

10. I feel **confident** in using information from the Internet to make health decisions

1) □ Strongly Disagree
2) □ Disagree
3) □ Undecided
4) □ Agree
5) □ Strongly Agree

Thank you!

COLLABORATIVE INSTITUTIONAL TRAINING INITIATIVE (CITI PROGRAM)

COMPLETION REPORT - PART 1 OF 2
COURSEWORK REQUIREMENTS*

* NOTE: Scores on this Requirements Report reflect quiz completions at the time all requirements for the course were met. See list below for details. See separate Transcript Report for more recent quiz scores, including those on optional (supplemental) course elements.

- **Name:** Olumayowa Odemuyiwa (ID: 4516432)
- **Institution Affiliation:** Auburn University (ID: 964)
- **Institution Email:** oao0004@tigermail.auburn.edu
- **Institution Unit:** Nursing
- **Phone:** 334-209-2515

- **Curriculum Group:** IRB # 2 Social and Behavioral Emphasis - AU Personnel - Basic/Refresher
- **Course Learner Group:** IRB # 2 Social and Behavioral Emphasis - AU Personnel
- **Stage:** Stage 1 - Basic Course
- **Description:** Choose this group to satisfy CITI training requirements for Key Personnel (including AU Faculty, Staff and Students) and Faculty Advisors involved primarily in Social/Behavioral Research with human subjects.

- **Record ID:** 30834865
- **Completion Date:** 10-May-2019
- **Expiration Date:** 09-May-2022
- **Minimum Passing:** 80
- **Reported Score*:** 91

REQUIRED AND ELECTIVE MODULES ONLY	DATE COMPLETED	SCORE
Belmont Report and Its Principles (ID: 1127)	02-May-2019	3/3 (100%)
The Federal Regulations - SBE (ID: 502)	03-May-2019	5/5 (100%)
Assessing Risk - SBE (ID: 503)	03-May-2019	4/5 (80%)
Informed Consent - SBE (ID: 504)	04-May-2019	4/5 (80%)
Privacy and Confidentiality - SBE (ID: 505)	05-May-2019	5/5 (100%)
Students in Research (ID: 1321)	05-May-2019	4/5 (80%)
Unanticipated Problems and Reporting Requirements in Social and Behavioral Research (ID: 14928)	10-May-2019	5/5 (100%)

For this Report to be valid, the learner identified above must have had a valid affiliation with the CITI Program subscribing institution identified above or have been a paid Independent Learner.

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COLLABORATIVE INSTITUTIONAL TRAINING INITIATIVE (CITI PROGRAM)

COMPLETION REPORT - PART 2 OF 2
COURSEWORK TRANSCRIPT**

** NOTE: Scores on this Transcript Report reflect the most current quiz completions, including quizzes on optional (supplemental) elements of the course. See list below for details. See separate Requirements Report for the reported scores at the time all requirements for the course were met.

- **Name:** Olumayowa Odemuyiwa (ID: 4516432)
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- **Stage:** Stage 1 - Basic Course
- **Description:** Choose this group to satisfy CITI training requirements for Key Personnel (including AU Faculty, Staff and Students) and Faculty Advisors involved primarily in Social/Behavioral Research with human subjects.

- **Record ID:** 30834865
- **Report Date:** 10-May-2019
- **Current Score**:** 91

REQUIRED, ELECTIVE, AND SUPPLEMENTAL MODULES	MOST RECENT	SCORE
Students in Research (ID: 1321)	05-May-2019	4/5 (80%)
Belmont Report and Its Principles (ID: 1127)	02-May-2019	3/3 (100%)
The Federal Regulations - SBE (ID: 502)	03-May-2019	5/5 (100%)
Assessing Risk - SBE (ID: 503)	03-May-2019	4/5 (80%)
Informed Consent - SBE (ID: 504)	04-May-2019	4/5 (80%)
Privacy and Confidentiality - SBE (ID: 505)	05-May-2019	5/5 (100%)
Unanticipated Problems and Reporting Requirements in Social and Behavioral Research (ID: 14928)	10-May-2019	5/5 (100%)

For this Report to be valid, the learner identified above must have had a valid affiliation with the CITI Program subscribing institution identified above or have been a paid Independent Learner.

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CITI PROGRAM

Completion Date 24-Nov-2017
Expiration Date 23-Nov-2020
Record ID 16433215

This is to certify that:

Maria Witte

Has completed the following CITI Program course:

IRB # 2 Social and Behavioral Emphasis - AU Personnel - Basic/Refresher (Curriculum Group)
IRB # 2 Social and Behavioral Emphasis - AU Personnel (Course Learner Group)
1 - Basic Course (Stage)

Under requirements set by:

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