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## **A Mixed Methods Study Of Health Literacy And Its Role In Hpv Vaccine Uptake Among College Students**

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*University of Alabama at Birmingham*

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A MIXED METHODS STUDY OF HEALTH LITERACY AND ITS ROLE IN HPV  
VACCINE UPTAKE AMONG COLLEGE STUDENTS

Michelle S. Williams

University of Alabama at Birmingham

Connie Kohler, Chair  
Monica Baskin  
Kathy Harrington  
Nataliya Ivankova  
Angela Jukkala  
Suzanne Martin

A Dissertation

Submitted to the graduate faculty of The University of Alabama at Birmingham.  
in partial fulfillment of the requirements for the degree of  
Doctorate of Public Health

BIRMINGHAM, ALABAMA

2014

A MIXED METHODS STUDY OF HEALTH LITERACY AND ITS ROLE IN  
HPV VACCINE UPTAKE AMONG COLLEGE STUDENTS

MICHELLE S. WILLIAMS

UAB SCHOOL OF PUBLIC HEALTH DEPARTMENT OF HEALTH BEHAVIOR

ABSTRACT

Health literacy includes the ability to understand and process written and spoken health information, and numbers and calculations related to health information. Low health literacy is associated with negative health outcomes, and poor patient-provider communication. In order to advance health literacy research, there is a need to assess health literacy comprehensively and to develop an understanding of how health literacy impacts people at various stages of their lives. A sequential explanatory mixed methods study was conducted to assess college students' health literacy. During the quantitative phase, the Short Test of Functional Health Literacy in Adults (S-TOFHLA), the Newest Vital Sign (NVS), the Cancer Message Literacy Test-Listening (CMLT-Listening), and the e-Health Literacy Scale (eHEALS) were used to assess the students' print literacy, health-related numeracy, aural cancer literacy, and eHealth literacy, respectively. During the qualitative phase, in-depth interviews were conducted with a subset of the original participants to obtain further evidence supporting the results of the literacy assessments and to identify factors in their social cultural environment that influence their health-related decisions including uptake of the Human

Papillomavirus (HPV) vaccine. During the quantitative phase, 160 students completed four health literacy assessments. The mean scores on the health literacy assessment were: S-TOFHLA: 35.2; CMLT-Listening: 82%; eHEALS: 80.9%; and NVS: 5.1. The scores of 3 of the 4 health literacy assessments were not correlated with their uptake of the HPV vaccine. Twenty students participated in in-depth interviews during the qualitative phase. The students' scores on the quantitative health literacy assessments indicated that they had adequate health literacy. However, the qualitative data showed that the students' cancer literacy, eHealth literacy, and numeracy skills were not as adequate as their health literacy test scores indicated. Furthermore, the qualitative data revealed that the majority of the students who had received the HPV vaccine had done so as the result of a recommendation from a healthcare provider or their parents. Therefore, it did not appear that they made an autonomous decision to get the HPV vaccine. The results of this study indicate that assessing health literacy using a one-dimensional approach may not accurately reflect college students' level of health literacy. In addition, students tend to rely on their aural literacy and eHealth literacy skills when seeking health information and making healthcare decisions. Therefore, there is a need for the development and implementation of intervention aimed at improving these skills among college students.

Keywords: health literacy, college students, cancer literacy, mixed methods

## DEDICATION

This dissertation is dedicated to my mother and the memory of my grandmother. Thank you for being the wind beneath my wings. Without your support I would not have been able to accomplish my goals. Thank you mom and dad for instilling a love of learning within me and supporting all of my endeavors. Thank you Larry for your love and support.

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## LIST OF ABBREVIATIONS

ACIP - Advisory Committee on Immunization Practices

CMLT-Listening – Cancer Message Literacy Test- Listening

eHEALS – eHealth Literacy Scale

FDA – Food an Drug Administration

HPV – Human Papillomavirus

IOM – Institute of Medicine

NVS – Newest Vital Sign

REALM – Rapid Estimate of Adult Literacy in Medicine

SPSS – Statistical Package for Social Science

STOFHLA – Short Test of Functional Health Literacy in Adults

TOFHLA – Test of Functional Health Literacy in Adults

## **Chapter 1: Introduction**

The Human Papillomavirus (HPV) is the most common sexually transmitted infection in the United States (Wu et al., 2012). Approximately 80% of adults in the US will be infected by at least one type of HPV at some time in their life (Gonzalez et al., 2008). More than 100 types of HPV have been identified. Some low-oncogenic risk strains of HPV are associated with non-life threatening health problems such as anogenital warts (Bosch et al., 2008). Several high-oncogenic risk strains of HPV are associated with the development of cervical, anal, oropharyngeal, vulvar, and penile cancers (Bosch et al., 2008; Castellsagué, 2008; Ho, Bierman, Beardsley, Chang, & Burk, 1998).

National data indicate that HPV-related cancers account for 3.3% (21,342) of all cancer cases among women and 2.0% (13,446) of all cancer cases among men (Jemal et al., 2013). Between 2000 and 2009, overall cancer incidence rates stabilized for women and declined for men (Jemal et al., 2013). However, the incidence of HPV-related oropharynx, anal, and vulvar cancers increased among men and women during that period (Jemal et al., 2013).

In 2006, the United States Food and Drug Administration (FDA) approved the use of the first vaccine that was developed to protect females from four common strains of HPV (Baylor, 2006). The quadrivalent vaccine (Gardasil®) was developed to protect against HPV-6 and -11, which cause genital warts, and HPV-16 and -18, which cause 70% of the cases of cervical adenocarcinoma (Barr et al., 2008; Bosch et al., 2008; Smith et al., 2007). In 2009, the FDA approved the use of the bivalent HPV vaccine (Cervix®) to protect females from HPV-16 and 18 (Centers for Disease Control and Prevention, 2010;

McKeage & Romanowski, 2011). Results from a large randomized control trial have shown that the bivalent vaccine can provide protection even in women who have been exposed to HPV (Paavonen et al., 2009). The FDA approved the quadrivalent HPV vaccine for use in males in 2008, since evidence indicated that it could also provide protection against HPV-related cancer of the mouth, throat, anus, and possibly the penis (Dunne et al., 2011).

The most recent data indicate that in Alabama the incidence of HPV-related diseases among females and males is higher than the national average (American Cancer Society, 2008). For example, between 2000 and 2009, the incidence of cancer of the mouth and throat among males in Alabama was 16.7 per 100,000, which is more than three times the national incidence of 9.2 per 100,000 (American Cancer Society, 2008). The incidence of cancer of the penis in Alabama was slightly higher than the national average (0.9 vs. 0.8, respectively) (American Cancer Society, 2008). The incidence of cervical cancer among women in Alabama is also higher than the national incidence rate (8.5 vs 7.8, respectively) (American Cancer Society, 2008).

The quadrivalent HPV vaccine can be given to girls and boys as young as 9 years old (Committee on Infectious Diseases, 2012). The Advisory Committee on Immunization Practices (ACIP) recommends that girls and boys get routine HPV vaccinations at age 11 or 12 (Committee on Infectious Diseases, 2012; Dunne et al., 2011). In addition, the ACIP recommends catch-up HPV vaccinations for females and males between the ages of 13 and 26 (Dunne et al., 2011; Markowitz et al., 2007).

Healthy People 2020 objective IID-11.4 is to “increase the vaccination coverage level of 3 doses of human papillomavirus (HPV) vaccine for females by age 13 to 15 years” to

80% (“Healthy People 2020,” 2010). Data on uptake of the HPV vaccine shows that vaccination rates of girls in the US have reached approximately 30%, but vary significantly by region of the country (Jemal et al., 2013). For example, only 20% (95% CI = 13.8% to 28.2%) of girls between the ages of 13 and 17 in Alabama that have completed a three dose HPV vaccine series (Jemal et al., 2013). National data show that only 1.4% of boys completed the three dose vaccine series in 2010 (Jemal et al., 2013).

Uptake of the HPV among emerging adults, people between the ages of 18 and 29, has been extremely slow. For example, Dempsey et al. (2011) found that 18% of female college students between the ages of 18 and 26 had initiated the 3-dose HPV vaccine series, and 10% had completed all three doses within 30 months. Since the HPV vaccine was approved for males, the uptake of the vaccine among college age males has also been extremely slow (Dorell et al., 2012). Previous studies of male college students found that the majority of participants were not aware that the HPV causes serious health problems in men, and they were not aware that the HPV vaccine was approved for preventing HPV-related diseases in males, (Crosby et al., 2012; Jones & Cook, 2008; Katz, Krieger, & Roberto, 2011; Krawczyk et al., 2012; Petrovic, Burney, & Fletcher, 2011).

The percentage of girls between the ages of 13 and 17 in Alabama that have completed the 3 dose series is 47.4% (95% CI: 34.3% to 60.9%) which is statistically significantly lower than the completion rates in other states in the South such as Georgia which had a 3 dose series completion rate of 70.9% (95% CI: 59.0% to 80.5%) (Jemal et al., 2013). The low HPV vaccination rates among adolescents have primarily been attributed to structural barriers including cost of the three dose series and the lack of health insurance (Deshpande, Sanders Thompson, Vaughn, & Kreuter, 2009; Downs,

Scarinci, Einstein, Collins, & Flowers, 2010; Gerend, Shepherd, & Shepherd, 2013; Hamlish, Clarke, & Alexander, 2012; Kushi et al., 2012; Sadigh, Dempsey, Ruffin, Resnicow, & Carlos, 2012). Several studies have also revealed common attitudinal and conceptual barriers to HPV vaccine uptake including the lack of knowledge about HPV, parenting norms, and parents' concerns about potential side effects (Brewer & Fazekas, 2007; Daley et al., 2011; Dempsey, Cohn, Dalton, & Ruffin, 2010; M. Katz, Krieger, & Roberto, 2011; Sanders Thompson, Arnold, & Notaro, 2012). One major drawback of these studies is that the majority of them focus on uptake of the HPV vaccine among adolescents.

Emerging adults, are in a period in their life during which they are becoming active consumers of healthcare for the first time (Arnett, 2000; Lam & Lefkowitz, 2013). During this developmental period, emerging adults must make decisions that will have "enduring ramifications" (Arnett, 2000). For example, the decision to get the HPV vaccine can provide protection against proximal health problems such as genital warts and distal health problems such as HPV-related cancers.

Previous studies regarding the uptake of the HPV vaccine among college students have identified barriers such as lack of knowledge about HPV and lack of perceived risk for HPV infection (M. Katz et al., 2011; M. L. Katz, Kam, Krieger, & Roberto, 2012; Lopez, 2007; Saules et al., 2007). In an attempt to increase uptake of the HPV vaccine, some universities and public health agencies have attempted to promote the vaccine via printed material and social media platforms. For example, Stock et al. (2013) developed an intervention aimed at increasing students' knowledge of HPV, oral sex and oral cancer via printed material. However, the effectiveness of printed material in promoting the

vaccine may be limited if students' health literacy is limited. Data from the National Survey of America's College Students found that 30% of 2-year college students and 20% of 4-year college students had basic or below quantitative literacy skills, which is the ability to interpret quantitative information such as numbers and calculations (Baer, Cook, & Baldi, 2006). It is possible that low vaccine uptake among this newly independent group of health consumers is related to their lack of knowledge about HPV and the vaccine. Lack of knowledge may be a result of poorly developed health literacy skills at this stage in their lives.

Ratzan and Parker (2000) define 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." However, as noted in the report, *Health Literacy: A Prescription to End Confusion*, health literacy arises from multiple factors including social and cultural factors. The report offers a framework for health literacy that shows how cultural and social factors influence health literacy along with educational and health systems. In supporting its Finding 4.1 (Culture gives meaning to health communication. Health literacy must be understood and addressed in the context of culture and language), the report asserts that health information and messages are shaped by perceptions and definitions of health and illness along with language, stereotypes and other barriers that arise from a person's culture. For example, a person's social norm influences whether he or she will engage in preventive health behaviors as well as where and what type of information they will look for and their interpretation of what they find (Nielsen-Bohlman, Panzer, & Kindig, 2004).



In addition, there are content and context specific types of health literacy, such as cancer literacy and eHealth literacy (Diviani & Schulz, 2011; Norman & Skinner, 2006). The most commonly studied components of health literacy are print literacy and numeracy. Although, all components of health literacy, including cultural and conceptual knowledge, play a vital role in healthcare decision making and ultimately health outcomes as indicated by Paasche-Orlow and Wolf's (2007) conceptualization of the causal pathways between limited health literacy and health outcomes. Furthermore, the PEN-3 model espouses that factors in a person's social cultural environment (e.g. beliefs and familial norms) influence their health behaviors (Airhihenbuwa, 1992).

Low health literacy has been shown to be a barrier to active engagement in preventive health behaviors, such as cervical cancer screening and uptake of the influenza vaccine (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011; Paasche-Orlow & Wolf, 2007; Sharp, Zurawski, Roland, O'Toole, & Hines, 2002). Currently, there is a lack of published studies that examine college students' health literacy skills in relation to the knowledge needed to process and act on information about the HPV vaccine. The purpose of this sequential explanatory mixed methods study is to comprehensively assess the health literacy of college students, to explore social cultural factors that may influence their cancer literacy in particular, and to determine the relationship between health literacy and the uptake of or intention to obtain the HPV vaccine. The goal of the quantitative phase of this study is to use health literacy tests to measure oral cancer literacy, print literacy, eHealth literacy, and health numeracy; and to determine if there is a relationship between the students' level of health literacy and their uptake of or intention to obtain the HPV vaccine. The goal of the qualitative phase of the study is to

conduct in-depth interviews in order to further explore college students' cancer literacy and to identify factors in their social cultural environment that influence the students' cancer-related health literacy and preventive health behaviors.

### **Specific Aims**

The specific aims of this study are to:

- 1) Comprehensively assess college students' aural cancer literacy, print literacy, eHealth literacy, and health-related numeracy.
- 2) Determine whether health literacy is a predictor of college students' uptake of or intention to obtain the HPV vaccine.
- 3) Identify social cultural factors that influence college student's cancer literacy and preventive health behaviors.

### **Definitions and Terms**

<i>Codebook:</i>	A compilation of the codes, their content descriptions, and a brief data example for reference (Saldana, 2013).
<i>Codes:</i>	Tags or labels for assigning units of meaning to the descriptive or inferential information compiled during a study (Miles & Hubberman, 1994).
<i>Confirmability:</i>	The relative neutrality and reasonable freedom from unacknowledged researcher biases (Miles & Hubberman, 1994).
<i>Confirmability audit:</i>	Using relevant queries to determine the ability of others to replicate the study (Miles & Hubberman, 1994). (i.e. Is there a record of the study's methods and procedures, detailed enough to be followed as an "audit trail?" (Schwandt &

Halpern, 1988))

<i>Credibility:</i>	Determining if the findings of the study make sense and if they are credible to the people that were studied (Miles & Hubberman, 1994).
<i>Dependability:</i>	The consistency and stability of the process of the study over time and across researchers and methods (Miles & Hubberman, 1994).
<i>Dependability audit:</i>	Using relevant queries to determine reliability. (i.e. Were coding checks made and did they show adequate agreement?) (Miles & Hubberman, 1994).
<i>Focused coding:</i>	A coding process for the latter stages of data analysis that both constantly compare, reorganize, or focus the codes into categories, prioritize them to develop “axis” categories around which others revolve (Saldana, 2013).
<i>Joint display:</i>	A figure or table containing both quantitative and qualitative data so that the two sources of data can be directly compared (Creswell & Plano Clark, 2011).
<i>Legitimation:</i>	The process of continuous evaluation throughout a mixed methods research project (Teddle & Tashakkori, 2009).
<i>Matrix:</i>	An illustrative display of data in rows and columns to see show how they interact (Miles & Hubberman, 1994).
<i>Maximum variation sampling:</i>	A sampling strategy that involves purposively selecting a wide range of cases to get full variation on dimensions of interest and to generate a diversity of comparisons (Teddle & Tashakkori, 2009).
<i>Mixing:</i>	The interrelating of a mixed methods study’s quantitative and qualitative phase (Creswell & Plano Clark, 2011).
<i>Peer debriefing:</i>	Dialogue with a disinterested peer about qualitative data as they are gathered and analyzed; results in the clarification of interpretations and identification of bias (Teddle & Tashakkori, 2009).
<i>Phenomenological study:</i>	A study that stresses the subjective experiences, social perceptions, and “naïve” analysis of events and phenomena by individuals (Heider, 1958).

<i>Reflexive journal:</i>	A diary of information about the investigator and the methodological decisions that the researchers make (Teddlie & Tashakkori, 2009).
<i>Sample integration:</i>	The extent to which the relationship between the quantitative and qualitative sampling designs yields quality meta-inferences (Teddlie & Tashakkori, 2009).
<i>Theme:</i>	The dominant feature or characteristic of a phenomenon under study (Teddlie & Tashakkori, 2009).
<i>Thick, rich descriptions:</i>	Context-rich and meaningful (“thick”) descriptions of the research settings (Creswell & Plano Clark, 2011).
<i>Transferability:</i>	The extent to which the conclusions of the study are transferable to other contexts (i.e. are the characteristics of the original sample of persons, settings, or processes fully described enough to permit adequate comparisons with other samples (Miles & Hubberman, 1994).
<i>Weakness minimization:</i>	The extent to which the weakness from one approach is compensated by the strengths from the other approach (Teddlie & Tashakkori, 2009).

## **Assumptions**

The following assumptions were made during the study:

- 1) Health literacy is important in healthcare decision-making.
- 2) Participants were honest when responding to questions on the study questionnaire regarding their HPV vaccine history or intention to get vaccinated.
- 3) Participants were honest when responding to questions during the in-depth interview.
- 4) Participants use information technology to access health information.

**Limitations.**

The use of qualitative data has inherent limitations. Potential limitations of qualitative data, include credibility, transferability, conformability, and dependability. The investigator took steps to minimize these biases, including the use of multiple coders and the maintenance of a reflexive journal. Another limitation of the study was that data were only collected from students enrolled at the University of Alabama at Birmingham (UAB). The students enrolled at UAB may not be representative of students enrolled at other universities in Alabama. Furthermore, the participants in the study were recruited from courses that were related to public health, health education, or nutrition and the majority of the students had a major related to those areas. Therefore, the participants may not be representative of students who do not have a major in those areas.

The possibility of recall bias is another limitation of this study. The questionnaire contained questions regarding the participants' HPV vaccine history. Some students may have experienced difficulty recalling whether or not they had received the vaccine. For example, during one in-depth interview, the participant revealed that they thought that they had received the HPV vaccine when they participated in an HPV vaccine study, but was not sure because the primary investigator of that study had never disclosed the group (experimental vs. placebo) that they were in.

During this study, the investigator became aware of the fact that a study being conducted in the UAB Lung Health Center was using the Newest Vital Sign (NVS) to assess health literacy. Therefore, it is possible that some participants may have been exposed to the NVS prior to enrolling in this study.

Finally, several UAB professors agreed to offer extra credit or bonus points as an incentive for participation in the quantitative phase of the study. Therefore, there may have been some degree of social desirability bias among students when responding to questions on the questionnaire.

### **Significance of the Study**

Disparities in HPV-related cancer incidence and mortality exist in Alabama (American Cancer Society, 2012a). Males and females in Alabama tend to have higher HPV-related cancer mortality rates, including cervical cancer and throat and mouth cancer than the national average (American Cancer Society, 2012b). The second phase in health disparities research is to identify the underlying factors (such as health literacy) that are driving these disparities (Thomas, Quinn, Butler, Fryer, & Garza, 2011). Therefore, this study will accomplish a significant component of health disparities research.

The quadrivalent HPV vaccine was approved for the prevention of HPV-related diseases in males and females between the ages of 9 and 26 (Baylor, 2006; Dunne et al., 2011). The results of clinical trials of the HPV vaccines indicate that they are a “high value” public health intervention (Schiller, 2012). However, completion of the 3-dose series has been significantly lower among adolescents in Alabama compared to adolescents in other states (Dorell et al., 2012). National data on rates of uptake of the HPV vaccine among people between the ages of 19 to 26 is not yet available. However, the results of previous studies aimed at investigating vaccine uptake within this population, indicate that rates of initiation and completion are very low. For example, Dempsey et al. (2011) found that among more than 11,000 women between the ages of

19 to 26 using primary care university based clinics, only 18% had initiated and 10% completed the three dose series at the time of the study.

Emerging adults have the ability to make their own health care decisions, which includes the uptake the HPV vaccine (Arnett, 2000). Low health literacy has been associated with lower engagement in preventive health behaviors (Berkman et al., 2011). Therefore, there is a need to conduct a comprehensive investigation to determine if health literacy, especially cancer literacy, is associated with the uptake of the HPV vaccine among emerging adults.

The results of this study will help to fill a major gap in the literature regarding health literacy and HPV vaccine uptake. The results of this study can also be used to develop culturally, and literacy-appropriate HPV vaccine education interventions for emerging adults.

## **Chapter 2: Review of Literature**

### **Introduction**

This chapter will provide a review of literature in the areas representing the major variables of interest and their relationships to one another: health literacy, HPV vaccine uptake, cancer prevention in relation to health literacy and HPV vaccine uptake, culture, and emerging adult health. The information discussed in this chapter represents the current literature, since 1990, and seminal research in the areas of health literacy, culture and health behaviors, and HPV vaccine uptake among adolescents and emerging adults. Studies were identified using PubMed and EBSCO.

### **Health Literacy**

Health literacy is the “degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions” (Ratzan, 2001). As depicted in Figure 1, health literacy is influenced by several factors that extend beyond the basic ability to read. Print literacy, oral/aural literacy, health numeracy, and cultural and conceptual knowledge interact to influence an individual’s health literacy (Nielsen-Bohlman, Panzer, & Kindig, 2004). Studies have shown that an individual’s literacy skills can predict their health status better than their demographic characteristics, including education level and age (Kirsch, Jungeblut, Jenkins, & Kolstad, 1993).



### **Health Outcomes Associated with Health Literacy.**

Functional health literacy is needed to successfully navigate the healthcare system, and to make healthcare decisions. However, data from the National Adult Literacy Survey revealed that the majority of adults in the US have low or marginal literacy (Kirsch et al., 1993). Furthermore, a disproportionately high percentage of racial and ethnic minorities have limited health literacy (Georges, Bolton, & Bennett, 2004). The results of several studies have indicated that low health literacy leads to poor health outcomes, lower patient compliance, and ultimately higher healthcare costs that burden individuals and the US healthcare system (Amalraj, Starkweather, Nguyen, & Naeim, 2009; Chin et al., 2011; Williams, Davis, Parker, & Weiss, 2002).

For example, Baker et al. (1998) found that patients with inadequate health literacy were more than twice as likely to be hospitalized as people with marginal or adequate health literacy.

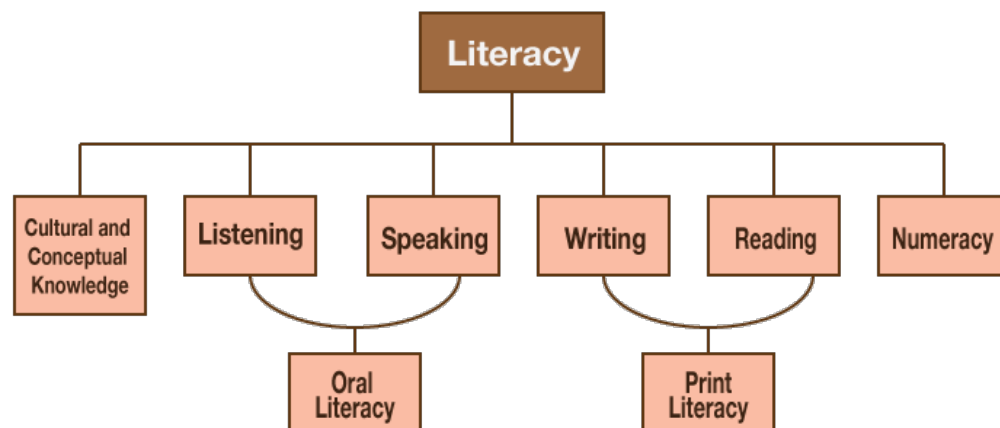


Figure 1. Components of Literacy from Nielsen-Bohlman, et al. (2004). Health Literacy: a prescription to end confusion.

Data from the health literacy assessments that were administered as a part of the National Assessment of Adult Literacy revealed that among adults 65 and older, low health literacy was associated with a lower likelihood of engaging in preventive health practices, such as obtaining the influenza vaccine, a mammogram and a prostate cancer screening (White, 2008). Zoellner et al. (2011) found that among adults living in a rural area in the Mississippi Delta, lower health literacy was associated with an increase in the consumption of sugar-sweetened beverages. Mitchell et al. (2012) found that health literacy was associated with 30-day hospital reutilization after initial discharge. Furthermore, Schillinger et al. (2002) found that low health literacy predicted poor health outcomes for people with diabetes, including poor glycemic control and the development of retinopathy.

### **Components of Health Literacy.**

Several tools for measuring health literacy have been developed to evaluate individual's health literacy skills. Some measures, such as the Short Test of Functional Health Literacy in Adults are objective measures of word recognition, basic numeracy, and reading comprehension (Nielsen-Bohlman, Panzer, & Kindig, 2004). Some health literacy tools, such as the eHealth Literacy Scale, are self-assessments of an individual's perceived literacy skills. It is important to note that none of the health literacy tools that are widely available were designed to assess multiple dimensions of health literacy nor were they designed to assess the cultural and conceptual knowledge related to health literacy.

### ***Print Literacy.***

Print literacy is the ability to read, write, and understand written language (Nielsen-Bohlman, Panzer, & Kindig, 2004). Print literacy is the most explored dimension of health literacy (Squiers, Peinado, Berkman, Boudewyns, & McCormack, 2012). The results of several studies have shown that people with adequate print literacy have better health outcomes because they are able to comprehend and act on health information, such as hospital discharge instructions (Amalraj et al., 2009; Chin et al., 2011; Peterson, Dwyer, Mulvaney, Dietrich, & Rothman, 2007).

People with low print literacy tend to benefit less from printed health information, such as the information that is found in pamphlets that are commonly placed in healthcare facilities (Boxell, 2012). Von Wagner et al. (2009) found that people with low print literacy had difficulty processing complex medical information. Print literacy is especially critical for people who have to manage chronic diseases, such as cancer survivors who must be able to obtain and comprehend information related to their care (Matsuyama, Kuhn, Molisani, & Wilson-Genderson, 2013). Therefore, inadequate print literacy can lead to decreased compliance to healthcare providers' recommended treatment regimens (DeWalt, Berkman, Sheridan, Lohr, & Pignone, 2004; Matsuyama, Kuhn, Molisani, & Wilson-Genderson, 2013; Shaw, Armin, Torres, Orzech, & Vivian, 2012).

### ***Health numeracy.***

Health numeracy is the degree to which individuals have the capacity to assess, process, interpret, communicate, and act on numerical quantitative, graphical,

biostatistical, and probabilistic health information needed to make effective healthcare decisions (Golbeck, Ahlers-Schmidt, Paschal, & Dismuke, 2005). Schapria et al. (2008) suggest that health numeracy is a multifaceted construct consisting of primary numeric skills, applied health numeracy, and interpretive health numeracy. Lipkus and Peters (2009) developed a conceptual framework of health numeracy which posits that there are six primary functions of health numeracy including: facilitates computation, encourages more information seeking and greater depth of processing, improves interpretation of the meaning of provided numbers, facilitates the assessment of likelihood and value, can increase or decrease acceptance of numerical data, promotes behavior change.

Individuals use their health numeracy skills when they are making healthcare decisions regarding the risks and benefits of certain healthcare activities, such as cancer screening, and adhering to treatment recommendations (Peters, Hibbard, Slovic, & Dieckmann, 2007; Reyna, Nelson, Han, & Dieckmann, 2009). People with lower health numeracy are more likely to report a lower health status than people with higher health numeracy (Manganello & Clayman, 2011).

Health numeracy is especially critical for the prevention and management of chronic diseases such as cancer (Gaglio, Glasgow, & Bull, 2012). For example, Kaplan et al. (2012) found that women with higher scores on an assessment of health numeracy were more willing to take breast cancer chemoprevention drugs than women with lower scores. Donelle et al. (2008) found that prose literacy and health-context numeracy were critical in the comprehension of internet-based colorectal cancer information. Furthermore, data from the National Cancer Institute's (NCI) Health Information Trends

Survey revealed that people with low objective and subjective health numeracy were less likely to obtain a colorectal cancer screening than participants with high health numeracy (Ciampa, Osborn, Peterson, & Rothman, 2010).

Although health numeracy is a significant component of health literacy, the majority of health numeracy studies that have been conducted have involved older adults. The few studies of the health numeracy skills of young adults suggest that health numeracy among emerging adults should be further investigated. For example, Sheridan and Pignone (2002) assessed the health numeracy skills of medical students and found that only 71% scored highly all components of the assessment.

### ***Aural Health Literacy.***

Aural health literacy, also referred to in the literature as oral health literacy, is defined as the ability to comprehend spoken health information (Baker, 2006). Aural health literacy is a significant domain of health literacy since studies have revealed that people of all literacy levels prefer to receive information during face-to-face interactions with healthcare providers, rather than from print materials, such pamphlets (Gaglio et al., 2012; Giuse, Koonce, Storrow, Kusnoor, & Ye, 2012).

There are few studies about the impact of aural health literacy on health behaviors. The results of previous studies of aural health literacy suggest that people who have low aural health literacy skills have an increased risk for mismanaging their healthcare. For example, Rubin et al. (2013) found that the degree to which people extract meaning from verbal health messages can impact how they act on information such as hospital discharge instructions. Rosenfeld et al. (2011) found that asthma

patients with lower aural health literacy skills had less successful management of their asthma.

### ***Cancer literacy.***

Cancer is currently the second leading cause of death in the US (Jemal et al., 2013). It is estimated that more than 1.6 million Americans were diagnosed with cancer in 2012 (Siegel, Naishadham, & Jemal, 2012). Despite this significant cancer burden, a concise, operational definition of cancer literacy does not exist (Diviani & Schulz, 2011).

Diviani et al. (2011) suggests that cancer literacy includes “all of the knowledge a layperson needs to possess to understand the information and advice the health system has to offer with regard to preventing, diagnosing, and treating cancer.” Using a Delphi study design, cancer experts completed three rounds of questionnaires to derive an operational concept of cancer literacy that includes (Diviani & Schulz, 2011): aspects of cancer risk (e.g., the strength of the relationship between risk factors and cancer development); aspects of information (e.g., trustworthiness of information sources about cancer); aspects of treatment (e.g., types of treatment); and aspects of coping with the disease (e.g., how to contact support services).

Williams et al. (2007) define breast and cervical cancer literacy as:

“A woman’s functional understanding of her personal and familial risk of the disease, including how to minimize her risk and the risk of her family through preventive early detection screenings and lifestyle changes and understanding how to access the health system and engage providers to minimize her risk and the risk of her family.”

Using this concept of breast cancer literacy, Mabiso et al. (2010) conducted a study to assess the breast cancer literacy of 161 African American women. The results of their study revealed that questions regarding breast cancer awareness were answered correctly 79.4% of the time, questions regarding breast cancer screening practices were answered correctly 79.5% of the time and questions regarding cancer prevention and control were answered correctly 86.6% of the time (Mabiso et al., 2010). The authors suggest that lower breast cancer literacy may be a barrier to screening for some African American women (Mabiso et al., 2010)

Helizter et al. (2012) suggest that individuals may have adequate health literacy regarding one illness, such as cardiovascular disease, but they may have inadequate health literacy regarding other health issues such as cancer. For example, Friedman et al. (2009) found that some African American men, who had adequate functional health literacy scores on the Short-Test of Functional Health Literacy for Adults (S-TOFHLA), had limited understanding of the risk factors and preventive behaviors for prostate cancer.

One of the primary research focal points of the National Cancer Institute's Comprehensive Cancer Centers is cancer communication (Hesse, 2009). However, there are a limited number of studies that have investigated cancer literacy and the public's ability to obtain, process and utilize cancer information.

### **eHealth Literacy**

The number of adults who seek health information on the internet has been steadily increasing as the internet has become more accessible to people throughout the US (Escoffery et al., 2005; Koch-Weser, Bradshaw, Gualtieri, & Gallagher, 2010;

McCully, Don, & Updegraff, 2013). Norman and Skinner (2006) define eHealth literacy 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.” The eHealth Literacy Lilly Model (Figure 2), illustrates the six facets of literacy that eHealth literacy encompasses (Norman & Skinner, 2006). These facets include traditional literacy, health literacy, information literacy, scientific literacy, media literacy, and computer literacy (Norman & Skinner, 2006).

Data from the NCI’s 2010 Health Information Trends Survey indicate that people who use the internet to obtain health information tend to be younger and have a higher level of education (Koch-Weser et al., 2010). Therefore, eHealth literacy is an important aspect of health literacy among emerging adults enrolled in college (Neter & Brainin, 2012; Norman & Skinner, 2006). However, the results of several studies indicate that the eHealth literacy of emerging adults is relatively low.

For example, in a study of Internet use among college students, Escoffery et al. (2005) found that 74% of the participants received health information from the internet, although, 89% of the participants did not always find the desired health information that they sought. Ivanitskaya et al. (2006) found that among college students attending a Midwestern university, the average score on the Research Readiness Self-Assessment, a measure of eHealth literacy, was 37 (54 was the maximum). Similarly, Hanik and Stellefson (2011) found that the scores on the eHealth Literacy Scale (eHEALS) of college students attending a university in the southwest ranged from 39.3% to 50.4% (100% was the maximum). The results of these studies warrant further investigation of the eHealth literacy skills of college students.



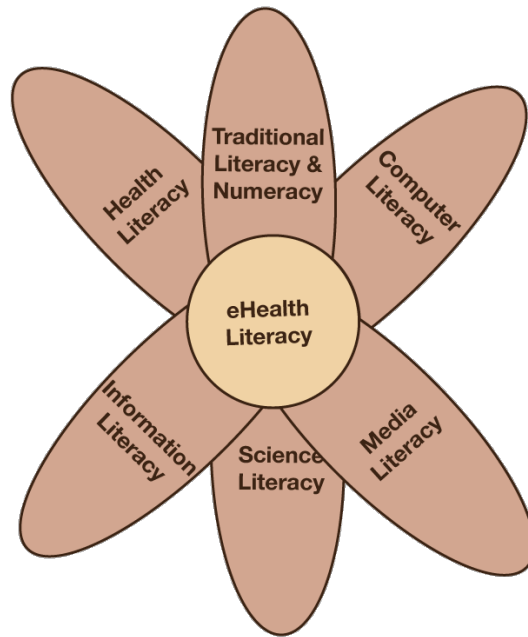


Figure 2. The Lilly Model of eHealth Literacy. from Norman & Skinner (2006). eHealth Literacy: Essential Skills for Consumer Health in a Networked World

### ***Health literacy and cancer prevention.***

The results of several studies indicate that health literacy is associated with awareness and knowledge of cancer and engagement in cancer prevention behaviors (Rogers, Wallace, & Weiss, 2006). For example, Boxell et al. (2012) found that women with low health literacy had low levels of gynecological cancer symptom awareness. Lindau et al. (2002) found that women with low health literacy had limited knowledge about cervical cancer risk reduction and the purpose of the Pap test.

People with limited health literacy are also less likely to obtain cancer screenings, and consequently have their cancer tumors diagnosed at more advanced stages than people with adequate health literacy. For example, Bennett et al. (1998) found that men who scored low on the Rapid Estimate of Adult Literacy in Medicine (REALM) were more likely to be diagnosed with advanced stage prostate cancer. Women's scores on the REALM were inversely associated with following-up on abnormal Pap test results (Lindau, Basu, & Leitsch, 2006). An analysis of data from the National Assessment of

Adult Literacy revealed that women between the ages 16 – 39 who had low health literacy were less likely to obtain a Pap test (White, Chen, & Atchison, 2008). Furthermore, in a qualitative assessment of the comprehension of cancer messages from television and radio, Mazor et al. (2010) found that overgeneralization, loss of details, and misunderstanding were common among the study participants.

### ***Health literacy in college students.***

The National Survey of America's College Students was conducted to examine the prose literacy, document literacy, and quantitative literacy of students enrolled in colleges and universities across the US (Baer, Cook, & Baldi, 2006). The results of the survey indicated that overall, 75 percent of students attending 2-year colleges and 50 percent of students attending 4-year colleges did not have a proficient level of literacy (Baer et al., 2006). Furthermore, the results revealed that there were significant disparities in the prose, document, and quantitative literacy between White students and African American students (Baer et al., 2006). For example, 34% of the African American students had basic and below basic prose literacy compared to 3% of the White students, and only 16% of the African American students had proficient prose literacy compared to 42% of the White students (Baer et al., 2006). This trend was the same for document literacy and quantitative literacy (Baer et al., 2006).

Relatively few studies have been conducted to investigate the health literacy of college students. The results of the studies that have been conducted have yielded mixed results regarding different components of health literacy. For example, Ickes and Cottrell (2010) used the Test of Functional Health Literacy in Adults (TOFHLA) to assess college

students' (n = 394) health numeracy and reading comprehension at a large Midwestern university. The results of their study indicated that the majority of the students (98.8%) in the study had adequate functional health literacy (Ickes & Cottrell, 2010). However, the average TOFHLA score of the African American students (M = 90.515) was lower than the average score of the white students (M = 94.227) (Ickes & Cottrell, 2010).

There is a lack of health literacy studies among college students that aim to assess skills other than print literacy and eHealth literacy. Furthermore, there is a lack of studies aimed at examining the relationship between college students' health literacy and health outcomes including cancer prevention behaviors, such as obtaining the HPV vaccine.

### **Culture**

There are many definitions of the term culture. One definition of culture is “the shared beliefs values, traditions, and behavior patterns of a particular group” (Peplau & Taylor, 1997). Culture includes the “understandings, symbols, material products, and practices of a group of people” (Smedley, Stith, Nelson, & Institute of Medicine (U.S.). Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care., 2003). Culture defines a person's reality and thus influences a person's perceptions, attitudes, and behaviors (Kagawa-Singer & Chung, 1994).

### **Culture and health behavior.**

Differences in health behaviors are often a function of culture (Deshpande, Sanders Thompson, Vaughn, & Kreuter, 2009). Understanding the ways in which culture influences the processing of health information and subsequent health behaviors is extremely important. Researchers have identified several social cultural constructs that

influence cancer-related beliefs, and cancer prevention and treatment behaviors (Airhihenbuwa, Kumanyika, Agurs, & Lowe, 1995; Holt, 2003; Peterson et al., 2007; Russell, Monahan, Wagle, & Champion, 2007). These social cultural constructs include racial pride, medical mistrust, perceived discrimination, spirituality/religiosity, time orientation, collectivism, and cultural identity (Holt, Lukwago, 2003; Deshpande et al., 2009).

For example, studies have found that cultural beliefs, such as “breast cancer is the will of God,” were associated with the detection of late stage breast cancer tumors in African American women (Bailey, Erwin, & Belin, 2000). Kinney et al. (2002) found that African American women who had high scores on the God Locus of Health Control Scale were less likely to adhere to breast cancer screening recommendations compared to women with lower scores. Holt et al. (2003) found that among a sample of African American women, mammography utilization was related to spiritual health locus of control and breast cancer beliefs.

Several studies have found that religious beliefs influenced African American parents’ decisions to vaccinate their children against HPV (Thompson et al., 2012; Thomas, Strickland, DiClemente, Higgins, & Haber, 2012; Thompson et al., 2011). In addition, studies have shown that fatalistic beliefs among African American women were associated with lower cervical cancer screening rates (Johnson, Mues, Mayne, & Kiblawi, 2008).

### **Culture and health literacy.**

Culture is the least explored dimension of health literacy. Cultural health beliefs play a significant role an individual’s perception of risk, response to health messages, and

health care decisions, all of which interact with health literacy. Previous research has shown that an individual's cultural model of health and illness can affect his or her scores on health literacy assessments (Shaw, Armin, Torres, Orzech, & Vivian, 2012). Factors such as level of education, socioeconomic status, and an individual's first language can affect how and when they look for health information, where they seek the information, the preferred type of information, and how they interpret the information (Nielsen-Bohlman, Panzer, & Kindig, 2004). The Institute of Medicine report, *Health Literacy: A Prescription to End Confusion* (Nielsen-Bohlman, Panzer, & Kindig, 2004) offers an explanatory model for the link between social cultural factors and health literacy. According to that report, a person's perceptions, definitions, and barriers are influenced by their culture and, in turn, contribute to the adequacy of their health literacy skills. Accordingly, when patients and providers (including those who develop health information) come from different cultural and educational backgrounds, problems in health literacy can arise.

The majority of studies that have been conducted to investigate the role of culture in health literacy have focused on immigrant populations or on chronic diseases other than cancer (Shaw, Huebner, Armin, Orzech, & Vivian, 2009). For example, Sentell et al. (Sentell & Braun, 2012) found that Latinos, Koreans, and Vietnamese with limited English proficiency were significantly more likely to have low health literacy compared to Whites. Furthermore, in qualitative interviews with African American participants, Shaw et al. (2012) found that many participants responded to questions on the S-TOFHLA by using their own concept of what the correct blood glucose level should be.

Their cultural beliefs about diabetes influenced how they interpreted the information that they read about diabetes.

An individual's social cultural environment plays a role in how they access, and interpret health information. This in turn influences their decisions to engage in cancer prevention activities. For example, Kreuter et al. (2006) found that African American women were 2.6 times more likely to obtain a mammogram after receiving magazines tailored on both cultural constructs (i.e. collectivism, religiosity, and time orientation) and behavioral constructs, than women who received magazines that were only tailored on either behavioral constructs or cultural constructs. Cultural beliefs that contradict conventional knowledge about cancer prevention may undermine cancer prevention interventions. Therefore, there is a need to further examine the role of culture in health literacy for all races and ethnicities.

## **Vaccine Uptake**

### **Vaccine uptake and health literacy.**

Vaccines have been proven to be highly effective at preventing several diseases including HPV-related cancers (Barr et al., 2008). Health literacy is related to the uptake of some vaccines (Howard, Sentell, & Gazmararian, 2006). For example, studies have shown that lower health literacy is associated lower uptake of the influenza vaccine (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011; White et al., 2008).

In a discussion of the importance of advancing vaccination coverage in the US by increasing health literacy, Ratzan (2011) stated:

“Vaccine literacy is not simply knowledge about vaccines, but also developing a system with decreased complexity to communicate and offer vaccines as sine qua non of a functioning health system. The goal is a change in social norm of advancing vaccine uptake, providing herd immunity with a foundation of vaccine/health literacy at a level commensurate with age, mental capacity, gender, and environment.”

There is a lack of studies that investigate the role of health literacy and the uptake of vaccines other than the influenza vaccine. Therefore, there is a need to examine the relationship between health literacy and uptake of the HPV vaccine.

#### **HPV related cancer prevention among college students.**

The Human Papillomavirus (HPV) is the most common sexually transmitted infection (STI) in the US (Ho, Bierman, Beardsley, Chang, & Burk, 1998). Low-risk strains of HPV are associated with the development of genital warts in females and males (Wu et al., 2012). High-risk strains of HPV are associated with the development of certain types of cancer in females and males including cancer of the cervix, mouth, throat, anus, and penis (Wu et al., 2012). The incidence of HPV infection and HPV-related cancers among adults in Alabama is higher than that of their counterparts living in other states (Howlader et al., 2012).

In 2006, the United States Food and Drug Administration (FDA) approved the use of a prophylactic vaccine, Gardasil®, that was developed to protect females from four common strains of HPV that are associated with genital warts and cervical cancer (Barr et al., 2008). The FDA approved Gardasil® for use in males in 2008 (Centers for Disease

Control and Prevention, 2012). The Advisory Committee on Immunization Practices has recommended the quadrivalent HPV vaccine for use in males and females between the ages of 11 and 26 (Dorell et al., 2012).

Immunizing females and males against HPV has the potential to lower the incidence of genital warts as well as the incidence of HPV-related cancers among women and men (Fontenot & Morelock, 2012; Kim & Goldie, 2008; Low, Attiga, Garg, Schlegal, & Gallicano, 2012). However, statistics show that in 2011, approximately 29.5% of women and 2.1% of men between the ages of 19 to 26 received at least one dose of HPV vaccine (“Adult vaccination coverage—United States, 2010,” 2012). Several studies have indicated that low uptake of the HPV vaccine among adolescents may be attributed to factors such as cost, lack of insurance, parents’ lack of knowledge about HPV, parenting norms, parents’ concerns about potential side effects, and lack of a healthcare provider’s recommendation for the vaccine (Fazekas, Brewer, & Smith, 2008; Sanders Thompson, Arnold, & Notaro, 2012; Thompson, Arnold, & Notaro, 2011). For example, in a qualitative study investigating mothers’ motivations to get the HPV vaccine for their daughters, Hamlish et al. (2012) found that failure of physicians to offer or to endorse the HPV vaccine was a significant challenge to initiating HPV immunization. (Sanders Thompson et al., 2012; Thompson et al., 2011). As previously discussed, relatively few studies have been done to investigate barriers to the uptake of the HPV vaccine among males and females over the age of 17.

Previous studies involving African American emerging adults suggest that disparities in HPV vaccine completion (i.e. receiving all three doses) are related to less knowledge about HPV and the HPV vaccine. Data from the 2007-2008 National Survey



of Family Growth indicate that African American women between the ages of 18 to 24 had lower awareness of HPV and the HPV vaccine than White women (80% vs. 90%) (Ford, 2011). D'Urso and her colleagues (2007) also found that there was a significant lack of awareness of HPV among African American male and female students at a Historically Black University. Daley et al. (2011) found that African American men had lower knowledge of HPV. Furthermore, the authors suggested, "Health literacy is a notable concept that emerged as a deficiency and may have contributed to lower levels of knowledge" (Daley et al., 2011).

Emerging adulthood is a time when people make life choices that will have ramifications later in their life (Arnett, 2000). Emerging adults, people between the ages of 18-29, who did not receive the HPV vaccine when they were adolescents, have the ability to obtain it using their own discretion. Therefore, understanding how the health literacy of emerging adults is related to the uptake of the HPV vaccine is a strategy to determine points of intervention.

## **Summary**

Health literacy consists of the skills needed to navigate the healthcare system and to make vital healthcare decisions. The majority of the studies that have been done to investigate health literacy have focused on print literacy, however, health numeracy, aural health literacy, health-context specific literacy, and eHealth literacy are also critical skills that influence healthcare choices.

The initiation and completion rates of the HPV vaccine are low among emerging adults. This may be attributed to underdeveloped health literacy skills, and low knowledge about HPV and the HPV vaccine among emerging adults. Since the incidence

of HPV infection is highest among women between the ages of 20 – 24, there is a need to increase HPV vaccination coverage in this population. However, there are significant gaps in the literature regarding the factors that influence the uptake of the HPV vaccine within this population.

## **Chapter 3: Research Design and Methods**

### **Overview**

Many studies have shown that health literacy is directly related to health outcomes and engagement in preventive health practices (Nielsen-Bohlman et al., 2004; Schapira et al., 2012; Sharp, Zurawski, Roland, O'Toole, & Hines, 2002). For example, studies have shown that patients with low health literacy are less likely to engage in cancer prevention activities, such as cancer screenings (Lindau, Basu, & Leitsch, 2006; Sharp et al., 2002; Shaw et al., 2009; Westin et al., 2008).

The majority of health literacy research has examined patients' ability to comprehend printed health information and patient forms (Shaw et al., 2009). Studies that focus on examining multiple components of health literacy or the influence of the social cultural environment on health literacy are lacking. Also, there is a lack of studies that investigate health literacy in specific contexts such as cancer.

Evidence shows that interventions aimed at promoting cancer screening and prevention behaviors, such as mammography, are more effective if they are culturally appropriate (Resnicow, Baranowski, Ahluwalia, & Braithwaite, 1999). The increase in the mortality rates for HPV-related cancers among men and women highlights the need to assess health literacy in a comprehensive manner so that culturally appropriate interventions for increasing uptake of the HPV vaccine can be developed.

The purpose of this sequential explanatory mixed methods study is to comprehensively assess the health literacy of college students and to determine the relationship between health literacy and the uptake of or intention to obtain the HPV vaccine. The goal of the quantitative phase of this study is to use health literacy tests to

measure aural cancer literacy, print literacy, eHealth literacy, and health numeracy; and to determine if there is a relationship between the students' level of health literacy and their uptake of or intention to obtain the HPV vaccine. The goal of the qualitative phase of the study is to conduct in-depth interviews in order to explore college students' cancer literacy and to identify factors in their social cultural environment that influence their health literacy and preventive health behaviors.

### **Research Questions**

The overall mixed methods research question is: How can quantitative data and qualitative data be used to comprehensively assess health literacy and the role that it has in the uptake of or intention to obtain the HPV vaccine among college students in Alabama? The specific research questions and the phase in which each will be addressed are listed in Table 1.

Table 1

*Research Questions*

Research Questions	Tools	Phase	
		Qualitative	Quantitative
Is the level of aural cancer literacy, print literacy, eHealth literacy, or health numeracy associated with the uptake of the HPV vaccine among female and male college students in Alabama?	CMLT-L eHEALS S-TOFHLA NVS Questionnaire		X
What factors in college students' social cultural environment affect the development of cancer literacy?	Interview guide	X	
What factors in college students' social cultural environment influence the uptake of the HPV vaccine?	Interview guide	X	

**Conceptual Framework**

Paasche-Orlow and Wolf (2007) developed a component-cause model that illustrated the causal pathways linking health literacy to health outcomes. Similar, to Neilsen-Bohlman's (2004) concept of health literacy, Passche-Orlow and Wolf's model depicted health literacy as being comprised of multiple components, but also included the systemic, interactional and self-care mechanisms that are involved with healthcare decisions and the subsequent health outcomes.

Due to the negative impact that low health literacy can have on health outcomes, Paasche-Orlow and Wolf (2007) called for investigators to "pursue research designs and analytic approaches to refine the model so that the most valid and useful explanations of

the relationship between health literacy and outcomes can inform professional responses to the problem in the many diverse contexts of health care.” The conceptual model that was developed for this study is an adaptation of Paasche-Orlow and Wolf’s original model and focuses on the relationship between the social cultural environment, four components of health literacy and decisions regarding uptake of the HPV vaccine. Figure 2 illustrates the conceptual model used in this study.

### **Explanation of the Conceptual Model.**

The conceptual model in Figure 3 illustrates that an individual’s social cultural environment, age, race/ethnicity, and education level have an influence their health literacy. Subsequently, health literacy affects an individuals’ access to and utilization of health information, interaction with healthcare providers, their self-care behaviors, and ultimately, their healthcare decisions and health outcomes. Passche-Orlow and Wolf’s original model included culture along with other factors such as occupation, income and language as influencing health literacy. In this model, the influence of culture on health literacy was emphasized. The concept of culture was replaced by the social cultural environment, which includes an individual’s health beliefs, attitudes, locus of control, and social networks. Another factor that distinguishes this model from Passche-Orlow and Wolf’s original model is that health literacy is differentiated into aural literacy, print literacy, eHealth literacy, and health-related numeracy. Furthermore, this model is patient centered, and therefore focuses on the patient factors related to access to and utilization of health information, provider-patient interaction, and self-care rather than system factors, provider factors, and extrinsic factors.

To illustrate the conceptual model, consider a 20 year-old (age), African American (race/ethnicity) female who is a third-year college student (education). She learned about the HPV vaccine in a health education class. She believes that she may be at risk for HPV since she is sexually active (health beliefs). She talks about the HPV vaccine with her mother, who tells her that it would be a good idea to get the vaccine (familial norms). After the conversation with her mother, she decides to obtain more information about the vaccine. She Googled the term HPV vaccine, and visited a few websites that appeared in the search results (eHealth Literacy). She reads the information on the websites and decides to make an appointment with her doctor to get more information about the vaccine (print literacy). While in the doctor's office, she asked her doctor to tell her about the potential risks of the vaccine (access and utilization of health information; and patient provider interaction). She decides that the benefits of the vaccine outweigh the risks of the vaccine and she decides to get vaccinated (self-care and HPV vaccine uptake).

As shown in figure 3, the constructs included in the green boxes labeled social cultural factors and health literacy were assessed during the quantitative phase and the qualitative phase. Since a sub-aim of this study was to assess the factors associated with college students' uptake of the HPV vaccine, the constructs in the orange boxes labeled accesses and utilization of health information, patient provider interaction and self-care were assessed in the qualitative phase of the study.

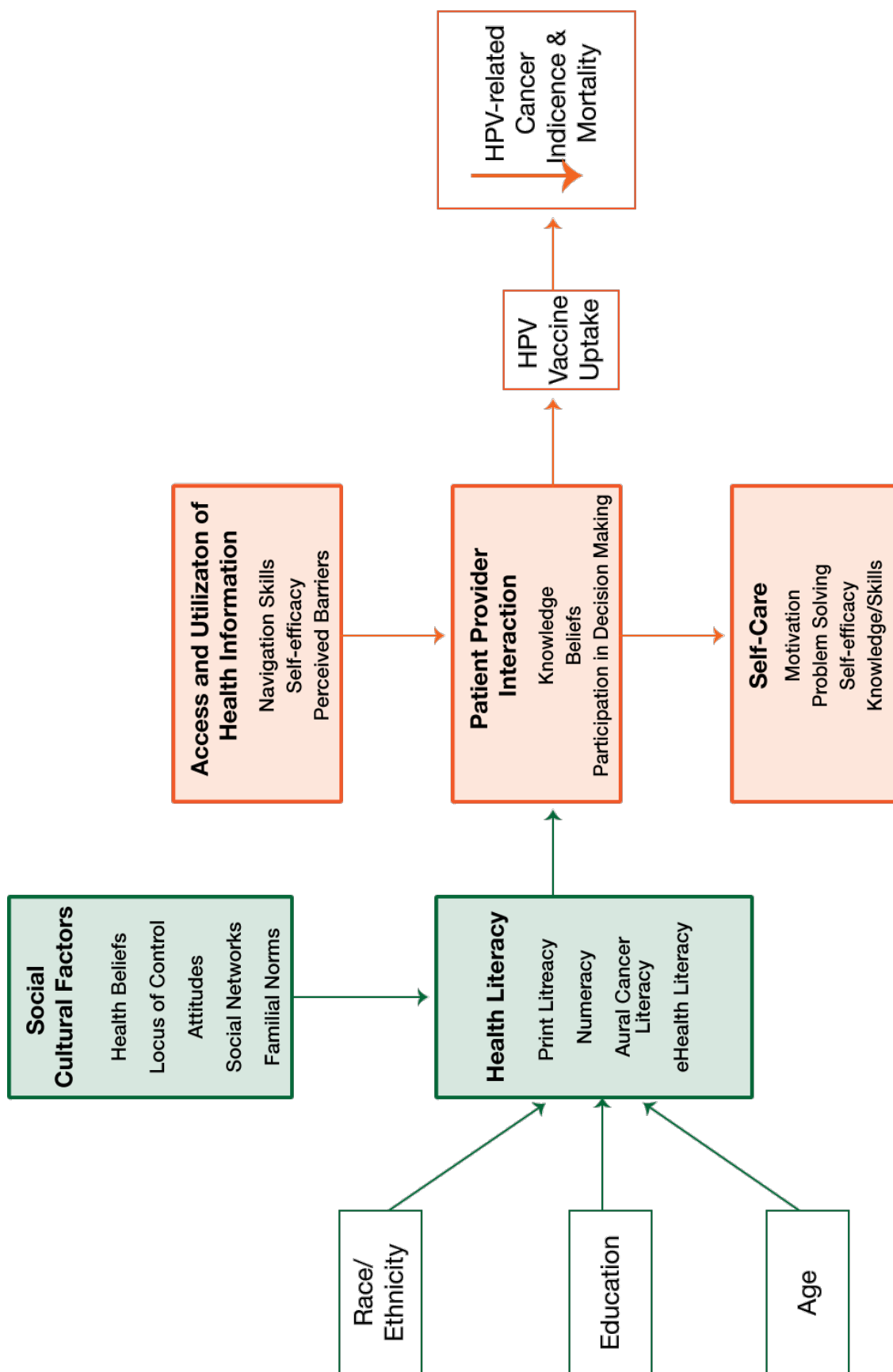


Figure 3. A conceptual model of the influence of health literacy on the uptake of, or intention to obtain, the HPV vaccine. Adapted from Passche-Orlow & Wolf (2007). Causal pathways between limited health literacy and health outcomes.



## **Research Design**

### **Mixed Methods Research.**

Mixed methods research involves the combination of quantitative and qualitative methods (Creswell & Plano Clark, 2011). Mixed methods research is based on the premise that combining qualitative and quantitative methods will produce a deeper understanding than either method could when used alone (Creswell & Plano Clark, 2011).

According to Smith (2009) “the current conceptualization and measures of health literacy miss much of the deeper meaning and purpose of literacy for health.” Therefore, the study of health literacy warrants a mixed methods approach. In this study, the investigator conducted a comprehensive assessment of health literacy that included an assessment of social and cultural factors that enable individuals to contextualize health problems and solutions (Airhihenbuwa, 2007).

Quantitative assessments of health literacy enabled the investigator to determine the participants’ level of aural cancer literacy, print literacy, eHealth literacy, and health numeracy. Additional quantitative data provided information about the participants’ knowledge of HPV, beliefs about HPV and the HPV vaccine, and sources of health information. Qualitative data allowed the investigator to develop a deeper understanding of the social cultural factors that influence health literacy and to thoroughly assess participants’ healthy literacy in a specific context (i.e. cancer literacy) (Creswell & Plano Clark, 2011). This would not have been possible with the use of quantitative assessments alone.

When using a mixed methods approach, researchers should use methods that have non-overlapping weaknesses (Creswell & Plano Clark, 2011; Greene, 2006; Johnson & Onwuegbuzie, 2004). Therefore, one weakness of quantitative data (inability to probe more deeply) is addressed through the addition of the qualitative phase while weaknesses of qualitative data (e.g. lack of generalizability, lack of the ability to replicate findings) are addressed through the quantitative phase.

### **Sequential Explanatory Design.**

A sequential explanatory mixed methods design is used when there is a need to collect qualitative data in order to provide an explanation of the significant or non-significant results of the quantitative phase (Bradley, et al., 2009; Morse, 1991).

The sequential explanatory design is also used to guide researchers who need to use quantitative results about participant characteristics to purposefully select participants for the qualitative phase (Creswell & Plano Clark, 2011).

A sequential explanatory design is ideal for this study since the overarching goal is to develop a comprehensive understanding of the role of health literacy in HPV vaccine uptake among college students. By using a sequential explanatory approach, the quantitative data collected from the psychometric assessments of the participants' aural cancer literacy, print literacy, eHealth literacy, and health numeracy can be explained with qualitative data about their social cultural environment.

Figure 4 illustrates the visual model for the sequential explanatory design used for this study (Creswell & Plano Clark, 2011). In this study, the same individuals participated in the quantitative phase and the qualitative phase. A minimum sample size of 150

college students was the recruitment goal for the quantitative phase in order to obtain a rigorous examination of health literacy. As recommended by Creswell and Plano Clark (2011), the qualitative sample size was smaller so that the investigator could conduct an in-depth exploration of the quantitative data. Twenty individuals who participated in the quantitative phase were selected to participate in the qualitative phase.

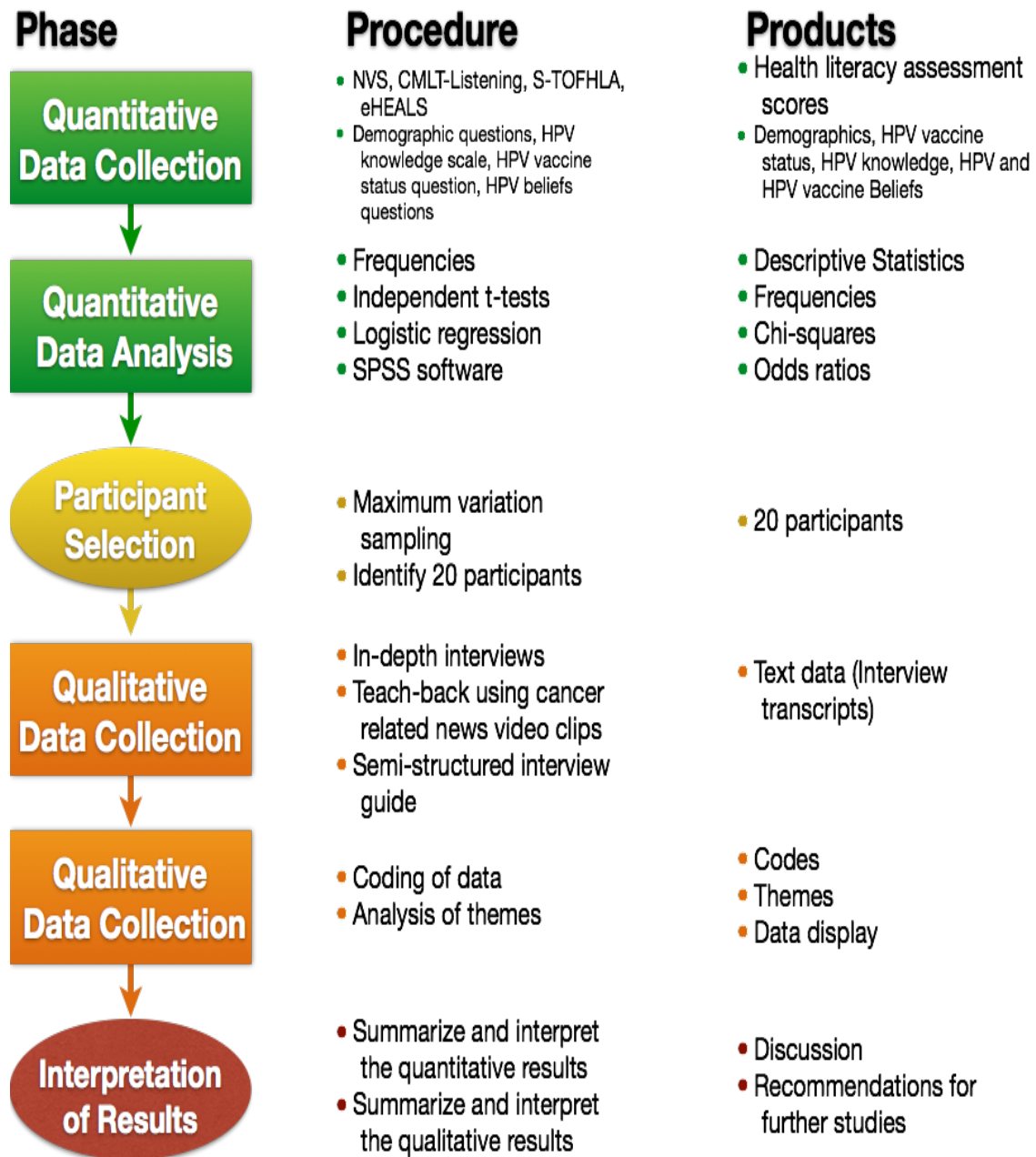
### **Study Setting**

This study was conducted on the campus of the University of Alabama at Birmingham (UAB). UAB is a research university that is located in Birmingham, Alabama. There are approximately 18,568 undergraduate and graduate students enrolled at UAB. Approximately, 60.6% (11,259) of the students are female and 39.4% (7,309) are male.

### **Sample and Participant Recruitment**

The eligibility criteria for study participants were: enrolled as a student at the University of Alabama at Birmingham; between the ages of 19 and 29; able to speak and comprehend English; having no significant physical or psychological disabilities that would prevent them from participating in the study. The investigator recruited male and female undergraduate and graduate students who were between the ages of 19 and 29 to participant in the study. Students were recruited through instructors during the 2013 summer and fall semesters. A website, [www.healthliteracystudy.org](http://www.healthliteracystudy.org), was created to serve a recruitment tool. The website contained information about the study, and provided interested student with the ability to register to participate in the study.

**Figure 4. Visual Model for Sequential Explanatory Design**



## **Quantitative Phase**

The quantitative phase of the study included the collection of the following data: demographic characteristics, health literacy test scores, HPV vaccine status, HPV vaccine intention, HPV knowledge, and beliefs about HPV and the HPV vaccine. The data collected during the quantitative phase was used to answer the research question, “Is the individual’s level of aural cancer literacy, print literacy, eHealth literacy, or health numeracy associated with uptake of or intention to obtain the HPV vaccine among college students?”

### **Data Collection.**

Quantitative data were collected to assess the participants’ print literacy, aural cancer literacy, eHealth literacy, and health numeracy. The four tools that were used to measure these components of health literacy are described below. The participants’ uptake of the HPV vaccine was assessed by three questions on the questionnaire that asked about the participants’ HPV vaccine history. For students who had not received the HPV vaccine, intention to obtain the HPV vaccine was assessed by two questions on the questionnaire that asked about the participants’ intention to get the HPV vaccine. The questionnaire was web-based and students were required to complete it before they attended a health literacy test session.

### **Instrumentation.**

#### ***eHealth Literacy.***

The eHealth Literacy Scale (eHEALS) is a self-assessment of a individual’s ability to find, evaluate, and apply electronic health information to their health problems

(Norman & Skinner, 2006). A copy of the eHEALS is located in Appendix A. The original version of the eHEALS consisted of 8-items. Norman and Skinner added two additional items to assess the participant's general interest in electronic sources of health information. This self-administered survey, including all ten items, takes approximately 3 minutes to complete. Norman and Skinner (2006) reported that the eHEALS has high internal consistency (Cronbach's  $\alpha = 0.88$ ) and modest test-retest reliability ( $r = .49$  to  $.68$ ).

### ***Print Literacy in the Context of Health Care.***

The Short Test of Functional Health Literacy of Adults (S-TOFHLA) was used to measure the participants' ability to read and understand written health information (Baker et al., 1999). A copy of the S-TOFHLA is located in Appendix B. Baker et al. (1999) found that the original S-TOFHLA had excellent internal consistency reliability (Cronbach's  $\alpha = 0.90$ ). The original S-TOFHLA also has excellent concurrent validity when compared to the full length TOFHLA ( $r = 0.91$ ) and good concurrent validity compared to the Rapid Estimate of Adult Literacy in Medicine (REALM) ( $r = 0.80$ ). The reliability and validity of the latest version of the S-TOFHLA which was used in this study has not been published.

The S-TOFHLA consists of two passages with missing words. The participant must read the passages and fill in the blank spaces with words from a multiple-choice list. The participant's score is based on the number of blanks that are filled in correctly. The participants have a maximum of 7 minutes to complete the S-TOFHLA. The scores for the S-TOFHLA and their corresponding health literacy levels are provided in Table 2.

Table 2

*Table Short-Test of Functional Health Literacy (S-TOFHLA)  
Health Literacy Levels and Scores*

Health Literacy Levels	Range of Scores	Functional Interpretation
Inadequate Functional Health Literacy	0 – 16	Able to read and interpret most health texts
Marginal Functional Health Literacy	17 – 22	Has difficulty reading and interpreting most health texts
Adequate Functional Health Literacy	23 – 36	Unable to read and interpret most health texts

***Aural Cancer Literacy.***

The Cancer Message Literacy Test-Listening (CMLT-Listening) was used to measure aural cancer literacy (Mazor, Roblin, et al., 2012; Mazor, Rogers, et al., 2012). The CMLT-Listening was developed to measure a person's comprehension of spoken messages related to cancer prevention and screening (Mazor, Roblin, et al., 2012). The original CMLT-Listening has been found to have good reliability (Cronbach's alpha = 0.85) (Mazor, Rogers, et al., 2012). A newly developed shorter version of the CMLT-Listening was also found to have good reliability (Cronbach's alpha = 0.85) (Mazor, 2013). In addition, the original CMLT-Listening is positively correlated to the REALM ( $r = 0.38$ ) (Mazor, Rogers, et al., 2012). This positive correlation indicates that the CMLT-Listening is a valid measure of health literacy since there is a positive relationship between the scores on the CMLT-Listening and the REALM.

The short version of the CMLT-Listening takes approximately 30 minutes to complete. The assessment begins with a brief introduction, which includes instructions for completing the assessment, and includes sample items for practice (Mazor, Roblin, et al., 2012). The short version of the CMLT-Listening consists of 10 cancer-related messages presented in videos and radio announcements. Each video or radio announcement has 2 or 3 associated questions for a total of 25 items (Mazor, 2013). Items contained in the short version of the CMLT-Listening are located in Appendix C. The CMLT-Listening is scored based on the percentage of questions that the participants answer correctly.

### ***Health Numeracy.***

The Newest Vital Sign (NVS) was developed to measure the risk for limited health literacy among patients (Weiss et al., 2005). The NVS assesses health numeracy, and the ability to make inferences about health information (Weiss et al., 2005). A copy of the NVS is located in Appendix D. Weiss et al. (2005), reported that the NVS has adequate internal consistency reliability (Cronbach's  $\alpha = 0.76$ ).

During the administration of the NVS, the participant is asked to review a nutrition facts label that represents information on a container of ice cream. The participant must use the information on the nutrition facts label to respond to six questions. It takes approximately 3 to 6 minutes to administer the NVS. The participants' scores are based on the number of questions that they answer correctly. The scores for the NVS and the corresponding health literacy levels are provided in Table 3.



Table 3

*Newest Vital Signs (NVS) Health Literacy Levels and Scores*

Health Literacy Levels	Range of Scores
High likelihood of limited literacy	0 – 1 correct answers
Possibility of low literacy	2 – 3 correct answers
Adequate literacy	4 – 6 correct answers

***Demographic Information.***

The questionnaire that was used to collect demographic data about the participants is located in Appendix E. The information that was collected is described in Table 4.

***HPV Knowledge***

A scale consisting of 15 items was used to assess the participants' knowledge of HPV. The scale was originally developed by Katz et al. (2011) to assess male college students' knowledge about HPV transmission, the health outcomes of HPV infection, the prevention of HPV transmission, and HPV infection treatment. Reliability of the scale was not reported in the manuscript that was published by Katz et al. (2011). Therefore, the investigator calculated the reliability of the scale based on the students' responses in this study. That information is provided in the results section. The scale is located on the questionnaire in Appendix E.

### ***Beliefs about HPV and the HPV Vaccine***

Items on the questionnaire, which is located in appendix E, were used to assess the participants' perceived risk of getting an HPV infection, perceived severity of HPV infections, outcome expectations of the HPV vaccine, perceived barriers to obtaining the HPV vaccine, and the subjective norms regarding the uptake of the HPV vaccine. Items from scales that were used to assess these constructs in similar populations were used (Jones & Cook, 2008; Patel et al., 2012).

Table 4  
*Demographic Survey Data*

Section	Data Collected
Demographic Characteristics	Age Gender Sexual Orientation Race and ethnicity Year in school Cumulative grade average Enrollment status Relationship status Marital status Health insurance status Number of children
Personal Health	General health status Health history Ever had sex HPV vaccination history HPV vaccine intention Cervical cancer screening history (females only) Time of last cervical cancer screening (females only)
Beliefs about HPV and the HPV Vaccine	HPV Awareness HPV Knowledge HPV Vaccine Awareness Perceived risk, severity, and barriers Subjective norms Outcome expectations

### **Sample Selection and Sample Size for the Quantitative Phase.**

The Creative Research Systems' (2014) sample size calculator was used to determine that a minimum sample size of 30 was needed to assess each of the major variables being investigated in the quantitative phase of this study. Because five major variables (print literacy test scores, health-related numeracy test scores, aural cancer literacy test scores, eHealth literacy test scores, and uptake of the HPV vaccine) were being investigated, it was determined that a minimum sample size of 150 students was needed. A purposive sampling strategy was developed to recruit at least 155 college students for the quantitative phase of the study (5 for the pilot test, 150 for quantitative phase). Students were recruited through courses in which they were enrolled.

### **Data Management and Analysis.**

An SPSS database was created and used to store the quantitative data. The quantitative data were analyzed using descriptive statistics and inferential statistics. Descriptive statistics were used to explore the quantitative data, describe the characteristics of the sample, and check the data for any violations of the assumptions underlying the statistical techniques that were used.

To compare the health literacy assessment scores of participants who had received the HPV vaccine and participants who had not received the HPV vaccine (Research Question 1), independent samples t-tests were computed. Independent samples t-tests were also computed to explore relationships between the participants' health literacy test scores, demographic characteristics, HPV knowledge, and vaccine status.

## **Qualitative Phase**

The qualitative phase of this study focused on exploring the social cultural factors that influence the development of health literacy. An understanding of the social cultural infrastructure of emerging adults is necessary for developing an understanding of the factors that influence the ways in which emerging adults process and use health information (Airhihenbuwa et al., 2009). Airhihenbuwa and Okoro (2008) define social cultural infrastructure as “non-market and nonphysical values that shape the moral and ethical codes by which relationships and expectations are defined, measured, and rewarded.” The social cultural infrastructure provides context and meaning for health information and serves as the basis for the adult’s perceptions and definitions that can influence the adequacy of their health literacy (Kreuter, Lukwago, Bucholtz, Clark, & Sanders-Thompson, 2003; Kreuter & Haughton, 2006; Nielsen-Bohlman, Panzer, & Kindig, 2004).

In addition, the objective of the qualitative phase was to develop a deeper understanding of the participants’ cancer literacy. The components of Diviani and Schulz’s (2011) operational definition of the concept of cancer literacy that were included in the interview guide were: aspects of cancer, aspect of cancer risk, aspect of information, and cancer treatment.

The qualitative phase provided data to answer the research questions, “What social cultural factors affect the development of cancer literacy of college students in Alabama?” and “What social cultural factors influence the uptake of the HPV vaccine among college students?”

### **Sample Size and Sample Selection for the Qualitative Phase.**

A maximum variation sampling strategy was used to select participants for the qualitative phase of the study. The maximum variation sampling process involved the selection of participants who range widely on the dimension of interest (Teddlie & Tashakkori, 2009). As shown in Figure 5, students were selected to participate in the qualitative phase based on scores on their race, gender, and HPV vaccine status (vaccinated vs. non-vaccinated).

The first selection criteria used in the sampling plan was race. The investigator aimed to select 10 African American students and 10 white students. Since the rate of HPV vaccine uptake is higher among females than among males, the investigator selected seven females and three males for each racial group. Vaccine status was the final selection criterion that was used for the sampling plan. Since there were no males who had obtained the HPV vaccine at the time the study was conducted, vaccine status was divided into the following three categories: vaccinated (received at least 1 dose of the HPV vaccine); intent (those students who intended to get the HPV vaccine); and no intent (students who had no intention of getting the HPV vaccine).

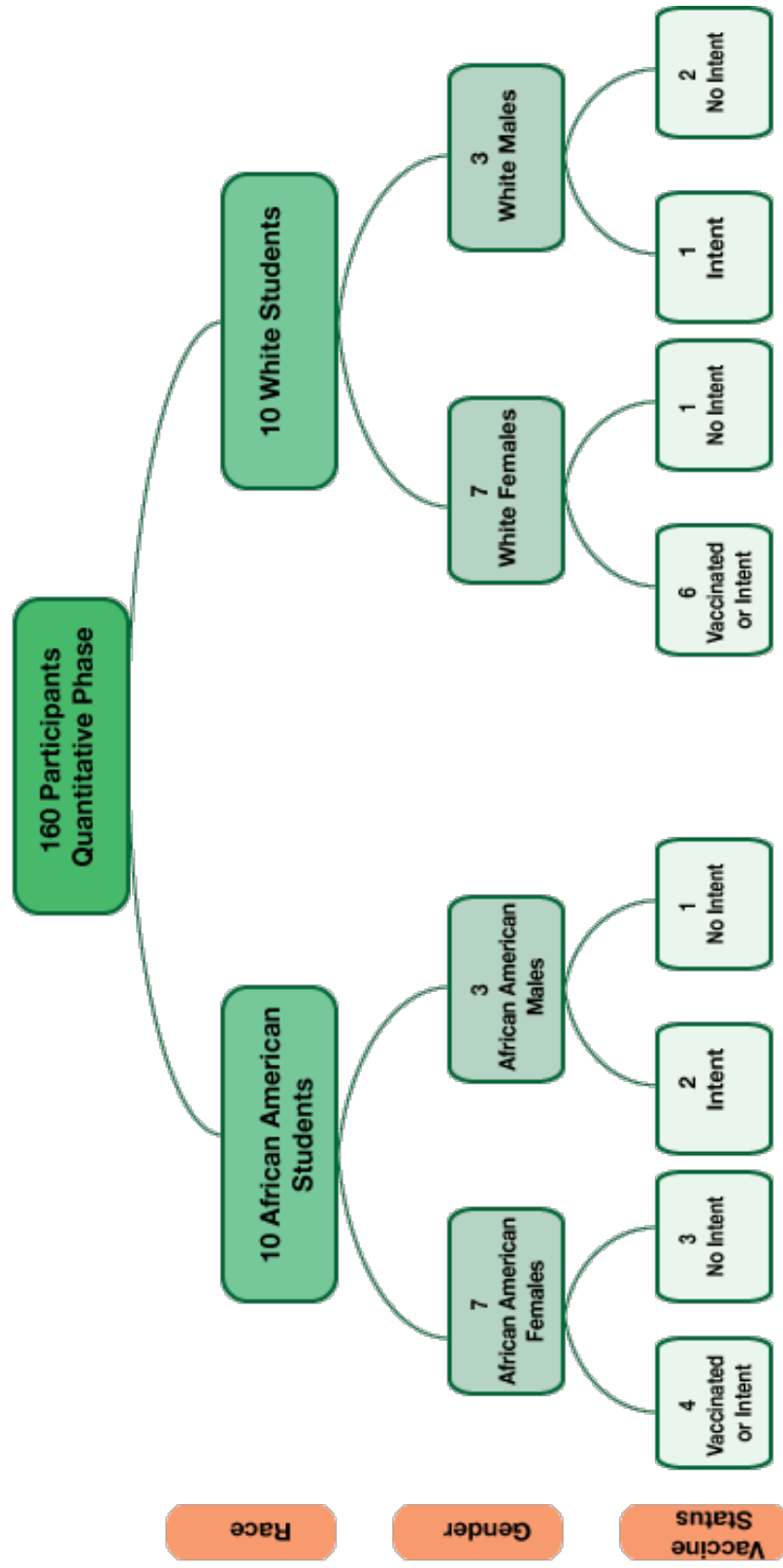
Recommendations for sample sizes of qualitative studies range from 3 to 25 participants (Creswell, 2013). For increased representativeness, a sample of 20 students was recruited for this study (Creswell, 2013). The investigator used data from the demographic questionnaire to categorize the participants according to the maximum variation sampling plan criteria. Students who met the criteria were contacted and invited to participate in an interview. If a student declined to participate in an interview, the next student meeting the criteria was contacted until the recruitment goal was achieved.

### **Instrumentation.**

The semi-structured interview guide that was used to gather the qualitative data was based on the theoretical framework of the PEN-3 model. The PEN-3 model was originally designed to aid in the development of culturally relevant health behavior programs in African countries (Airhihenbuwa, 1989). The PEN-3 model has been frequently used to guide the development of culturally appropriate health promotion interventions for African Americans and other racial/ethnic minorities in the US, including cancer screening interventions (Abernethy et al., 2005; Garces, Scarinci, & Harrison, 2006; Kline, 2007; Kline & Huff, 2007). To date, there are no published studies that have used the PEN-3 model for studies that included white participants. The results of studies that used the PEN-3 model indicate that it is an appropriate theoretical framework for assessing how the social cultural infrastructure can influence a person's health behaviors (Kline & Huff, 2007). Everyone, regardless of their race or ethnicity, has a culture; therefore, using the PEN-3 in a study that includes white participants should not be a limitation.

The PEN-3 model consists of three dimensions of health beliefs and behaviors. These dimensions are called: cultural empowerment, relationships and expectations, and cultural identity (Airhihenbuwa & Okoro, 2008). Each dimension consists of three categories that form the PEN-3 acronym. Figure 6 illustrates the PEN-3 model and highlights the fact that the three dimensions interact with each other (Airhihenbuwa, 1993).

Figure 5. A diagram of the maximum variation sampling plan



The cultural identity dimension is used to determine if the point of intervention entry should be the person, the extended family, or the neighborhood (Airhihenbuwa & Okoro, 2008; Kline & Huff, 2007). The relationships and expectations dimension is used to identify perceptions, enablers, and nurturers that act as facilitators and barriers to the health behavior being investigated. The cultural empowerment dimension is used to identify positive, existential, and negative values, beliefs, and relationships related to the health behavior under investigation.

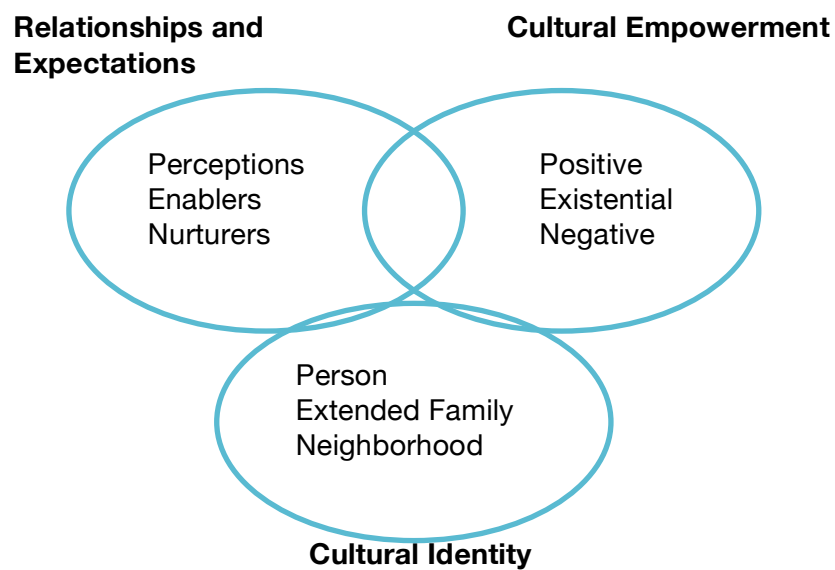


Figure 6. PEN-3 model, a conceptual model for culturally sensitive and culturally appropriate health promotion and disease prevention. From “Health Issues in the Black Community,” by R. Braithwaite and S. Taylor, 1992, Jossey-Bass, p. 272. Copyright 1992 by Jossey-Bass



When using the PEN-3 model to develop an intervention, investigators must first identify the manner in which the relationships and expectations dimension and the cultural empowerment dimension interact (Airhihenbuwa & Okoro, 2008). These two dimensions are referred to as the assessment phase. The cultural identity dimension is referred to as the intervention phase because it is used to determine the best point of entry for the intervention (Airhihenbuwa & Okoro, 2008). As depicted in the study's conceptual model (Figure 3), social cultural factors, such as health beliefs and familial norms, influence health literacy and subsequently the uptake of the HPV vaccine.

For this study, the two dimensions in the assessment phase of the PEN-3 model were used to identify the social cultural factors that may be associated with the health literacy and uptake of the HPV vaccine among college students. The components of these two dimensions of the PEN-3 model and examples of how they were applied to the study are listed in Table 5.

Table 5

*The Assessment Phase of the PEN-3 Model and Applications to the Study*

Relationships and Expectations	
Categories	Application to the Study
Perception	Identify the knowledge, attitudes, values, and beliefs that may facilitate HPV vaccine uptake.
Enablers	Determine the availability and accessibility of the HPV vaccine.
	Identify other cultural, societal, systematic, and structural influences that may enhance or hinder the uptake of the HPV vaccine.
Nurturers	Identify the extent to which extended family, kin, peers, and community members influence health beliefs, attitudes, and actions related to the HPV vaccine and cancer prevention.
Cultural Empowerment	
Categories	Application to the Study
Positive	Identify the positive aspects of culture that influence the uptake of the HPV vaccine.
Existential	Identify the cultural values and beliefs about cancer that do not have a negative effect.
Negative	Identify negative values and relationships that produce negative health outcomes related to the HPV vaccine cancer prevention.

### **Data Collection Procedures.**

A subset of the students who participated in the quantitative phase was selected to participate in the qualitative phase. The qualitative phase began after the quantitative phase ended, when all of the participants had attended a health literacy test session.

The researcher conducted an in-depth interview with each of the selected participants. The average length of the interview was 30 minutes. The interviews were held in a secluded, private room in the School of Public Health building or the Lister Hill library. All interviews were audio and video recorded.

During the first part of the interview, the investigator used a semi-structured interview guide (see Appendix F) to generate a discussion with the participants by using open-ended (qualitative) questions. The structure of the discussion guide allowed the investigator to probe deeply where necessary and follow new topics that arose (Morgan, 1997). The interview guide consisted of questions aimed at gathering information related to the following content domains: cancer literacy (aspects of cancer, aspects of health information, and aspects of cancer treatment); PEN-3 model assessment domains (enablers and nurturers who may influence uptake of the HPV vaccine and other healthcare decisions; positive, existential, and negative beliefs that may influence uptake of the HPV vaccine and other healthcare decisions); and sources of health information;.

To further explore the students' aural cancer literacy skills, the teach-back technique was used during the second part of the interview. The teach-back technique required the participant to watch a brief video and then explain the meaning of the video in his or her own words. The first video that was presented was a public message about HPV vaccine uptake among women. The video was used in the short version of the CMLT-Listening.

The second video that was presented was a public message about the health effects of HPV infection in men. The video was obtained from the website of a national television news broadcast channel. The transcripts for the videos are located in Appendix F.

### **Data Management and Analysis.**

The researcher transcribed the recordings of the interviews. After each interview, the researcher recorded thick, rich descriptions of the interview in the reflective journal. Thick, rich descriptions are context-rich and meaningful (“thick”) descriptions of the research settings (Creswell & Plano Clark, 2011).

During the first round of coding, an in-vivo coding process was used to code the data. In-vivo coding (not to be confused with the software, NVivo) is coding by using the participants’ own words. The codebook that was generated is located in Appendix I. Then, a focused coding process was used to code the data according to the theoretical frameworks used for the qualitative phase, Diviani and Schulz’s conceptual definition of cancer literacy and the PEN-3 model (Saldana, 2013). Focused coding is a coding process for the latter stages of data analysis that a) constantly compares, reorganizes, or focuses the codes into categories, b) prioritizes them to develop “axis” categories around which others revolve, and c) synthesizes them to formulate a central or core category (Saldana, 2013). The qualitative data were coded; a codebook was created; and the major themes were arranged in a 3x3 matrix (Miles & Hubberman, 1994). A display of the most common themes that occurred in the transcripts was generated. No existential perceptions, enablers or nurturers emerged during the data analysis. Therefore, the table includes positive and negative perceptions enablers and nurturers. It is located in Appendix G.

## **Legitimation**

Onwuegbuzie and Johnson (2006) use the term legitimation to describe the “dynamic and iterative process of evaluation for demonstrating the quality of inferences in mixed methods research.” Lincoln and Guba (1985) developed criteria for evaluating and enhancing the quality of inferences made about qualitative data. To ensure that the inferences made about the qualitative data collected in this study are valid (i.e. ‘legitimate’), four criteria were used to judge to their quality. The criteria that were used in this study are discussed below.

In qualitative research, the term credibility is used to describe methods used to determine if the findings of the study make sense and if they are credible to the people who were studied (Miles & Hubberman, 1994). In quantitative research, internal validity is the analogue for credibility. Credibility can be enhanced by using several techniques such as peer debriefing (Miles & Hubberman, 1994) (see definition of terms). In this study, peer debriefing was conducted when the investigator discussed findings with the committee chair during the data analysis process.

Transferability is defined as the extent to which the conclusions of the study are transferable to other contexts (i.e. are the characteristics of the original sample of persons, settings, or processes fully described enough to permit adequate comparisons with other samples) (Miles & Hubberman, 1994). In quantitative research, external validity is the analogue for transferability (Miles & Hubberman, 1994). The transferability of qualitative data can be enhanced by developing thick, rich descriptions of the context and other aspects of the setting in which the qualitative data collection occurs (Teddle & Tashakkori, 2009). According to Miles and Hubberman (1994), thick, rich descriptions

will enable the “readers to assess the potential transferability, appropriateness for their own settings.” In this study, the researcher developed thick, rich descriptions of the context in which the interviews occurred (Teddlie & Tashakkori, 2009).

Dependability is the consistency and stability of the process of the study over time and across researchers and methods (Miles & Hubberman, 1994). In quantitative research, dependability is analogous to reliability (Miles & Hubberman, 1994). In this study, dependability was established by doing a dependability audit, which involved using relevant queries to determine reliability. (i.e., were coding checks made and did they show adequate agreement?) (Miles & Hubberman, 1994). To ensure consistency two additional coders reviewed 5 of the transcripts that the investigator coded. Discrepancies in the codes were discussed and resolved.

Confirmability is the relative neutrality and reasonable freedom from unacknowledged researcher biases (Miles & Hubberman, 1994). In quantitative research, the analogue for confirmability is objectivity (Miles & Hubberman, 1994). In this study the researcher established confirmability by conducting a confirmability audit to ensure that the interpretations were supported by the results and were internally coherent (Teddlie & Tashakkori, 2009). During the confirmability audit, the following query was addressed: “Has the researcher been explicit and as self-aware as possible about personal assumptions, values and biases, affective states-and how they may have come into play during the study?” In addition, the researcher maintained a reflexive journal throughout the study. A reflexive journal is a diary of information about the investigator and the methodological decisions that the researcher makes (Teddlie & Tashakkori, 2009). The reflexive journal was used to determine if the “actual sequence of how data were

collected, processed, condensed/transformed, and displayed for specific conclusion drawing” could be followed (Miles & Hubberman, 1994).

Sample integration was used to overcome the potential threats caused by data collection issues (Teddlie & Tashakkori, 2009). Sample integration is the extent to which the relationship between the quantitative and qualitative sampling designs yields quality meta-inferences (Teddlie & Tashakkori, 2009). The researcher drew the samples for the qualitative phase from the quantitative sample and addressed similar questions in both phases of the data collection (Morse, 1991).

Weakness minimization was used to overcome threats to the validity of the meta-inferences by using questionnaires and interviews to collect data (Johnson & Turner, 2003). Weakness minimization is the extent to which the weakness from one approach is compensated by the strengths from the other approach (Teddlie & Tashakkori, 2009). For example, one weakness of a paper and pencil survey is that the respondent may provide vague answers to open-ended items (Johnson & Turner, 2003). The use of interviews can overcome this weakness because interviewers can probe for more specific, in-depth information (Johnson & Turner, 2003).

### **Research Permission and Ethical Considerations**

Approval from the UAB Institutional Review Board was granted prior to the recruitment of participants. Participants were provided with an informational sheet that described the purpose of the study and contained the contact information for the primary investigator. The investigator reviewed the informed consent form with each participant

and notified them of their right to withdraw from the study at any time. Written consent was obtained prior to data collection.

The investigator ensured that all data were kept confidential and all identifying information was stored separately from the databases. Hardcopies of the data were stored in a locked file cabinet. The electronic data was stored on a password protected laptop computer.

### **Feasibility of the Study**

Participants were recruited through courses in which they are enrolled. Participant recruitment may was a challenge. Therefore, getting buy-in from the professors aided the efforts to recruit participants.

The Lister Hill Library and Sterne Library at UAB contain a wealth of resources that can be used for this study including mixed methods textbooks, health behavior theory textbooks, and peer-reviewed journals. Additional resources that may be needed will be purchased with funds from the CPCTP.

Prior to that the investigator completed three qualitative research courses at the University of Michigan's Summer Institute in Survey Research Techniques, which included a course titled *Qualitative Analysis With and Without Computers*. Also, the investigator has extensive experience analyzing quantitative data with SPSS.



## Chapter 4: Results

# **Manuscript 1: A comprehensive assessment of college students' health literacy using a mixed methods approach**

## **Abstract**

**Objective:** To conduct a comprehensive assessment of college students' print literacy, health-related numeracy, eHealth literacy, and aural cancer literacy.

**Participants:** Participants were 160 college students at a large, urban university in the southeast.

**Methods:** The Short Test of Functional Health Literacy in Adults (S-TOFHLA), the Newest Vital Sign (NVS), the Cancer Message Literacy Test-Listening (CMLT-Listening), and the e-Health Literacy Scale (eHEALS) were used to assess the students' (n = 160) print literacy, health-related numeracy, aural cancer literacy, and eHealth literacy, respectively. In-depth interviews were conducted with a subset of the original participants (n = 20) to further assess their health literacy skills.

**Results:** The mean assessment scores were: S-TOFHLA: 35.2; CMLT-Listening: 82%; eHEALS: 80.9%; and NVS: 5.1. Twenty students participated in in-depth interviews. The qualitative data indicated that students had inadequate aural cancer literacy, eHealth literacy, and numeracy skills.

**Conclusion:** The health literacy assessments scores indicated that the participants had adequate health literacy. However, the qualitative data indicated that some students had inadequate eHealth literacy, health-related numeracy and aural cancer literacy skills.

**Keywords:** health literacy, college students, mixed methods

Health literacy is the ability to obtain, process and use the health information that an individual needs to make healthcare decisions.<sup>1</sup> An adequate level of health literacy is necessary to successfully navigate the healthcare system and make effective healthcare decisions. Health literacy is multidimensional and consists of the ability to understand and process written health information (print literacy), spoken health information (aural literacy), and numbers and calculations related to health information (numeracy).<sup>2</sup> Since access to the internet has increased significantly over the last two decades, the ability to adequately obtain, evaluate and use health information from the electronic sources to solve health problems (eHealth literacy) is also an important component of health literacy.<sup>3</sup>

Several studies have shown that people with low health literacy are more likely to experience negative health outcomes, have poor communication with health care providers, and experience difficulty navigating the healthcare system.<sup>4-8</sup> For example, data from young adults who completed the Health Information National Trends Survey in 2008, indicated that people with lower numeracy were more likely to report being frustrated when searching the internet for health information, having lower overall health status, and having less trust in their doctors than people with higher numeracy.<sup>9</sup> People with adequate health literacy are more likely to engage in preventive health behaviors such as obtaining vaccines and cancer screenings.<sup>10,11</sup>

Several measures for assessing the individual components of health literacy have been developed and validated. For example, one of the most common measures that is used in health literacy research is the Test of Functional Health Literacy in Adults (TOFHLA), which has been found to be a valid and reliable measure of an individual's

ability to read printed health-related material.<sup>12</sup> Other health literacy assessment tools that have been used in research and in clinical settings include the Rapid Estimate of Adult Literacy in Medicine (REALM), which is used to assess patients' ability to recognize and pronounce medical terminology, and the Newest Vital Sign (NVS), which is used to assess patients' general literacy and health-related numeracy.<sup>13,14</sup> Furthermore, some measures have been developed to assess health-context specific literacy, such as cancer literacy. For example, Mazor et al.<sup>15</sup>, developed two Cancer Message Literacy Tests (CMLT) to assess an individual's ability to understand written (CMLT-Written) and spoken cancer messages (CMLT-Listening).

Functional health literacy involves an integration of health literacy skills.<sup>2,16,17</sup> For example, Rosenfeld<sup>18</sup> found that both aural literacy and print literacy were important in the management of asthma. Furthermore, factors in an individual's social cultural environment such as familial norms, influence their health literacy.<sup>10,10,19</sup> For example, in a study of the impact of cultural differences on health literacy and chronic disease outcomes, Shaw et al.<sup>10</sup> found culture affects the way in which people in different ethnic groups process and respond to health messages. However, none of the health literacy assessment tools that are readily available, provide a comprehensive assessment of patients' health literacy or collect data on factors in the patient's social cultural environment.<sup>20</sup>

The majority of health literacy studies have involved middle age and older adults.<sup>21</sup> However, health literacy is a vital skill for people of all ages.<sup>2</sup> In order to advance health literacy research, there is a need to assess health literacy comprehensively and to develop an understanding of how health literacy impacts people at various stages

of their lives.<sup>20,22,23</sup> Emerging adults, people between the ages of 18 to 29, must make important healthcare decisions that could have immediate and long-term repercussions, such as the decision to obtain the HPV vaccine.<sup>24</sup> The purpose of this study was to conduct a comprehensive assessment of college students' health literacy using a sequential explanatory mixed methods research design.

To the best of our knowledge, this is the first study to examine the health literacy of emerging adults in a comprehensive manner. During the quantitative phase, four measures were used to assess the students' print literacy, aural cancer literacy, health-related numeracy, and eHealth literacy. In the qualitative phase of the study, in-depth interviews were conducted with a subset of the original participants in order to obtain further evidence supporting the results of the literacy assessments and to identify factors in their social cultural environment that influence their health literacy and their health-related decisions, such as getting the HPV vaccine.

## **Methods**

### *Participant selection*

Students between the ages of 19 and 29 were recruited from a midsize, urban university in the Southeast. During the summer and fall semesters of 2013, instructors teaching health education, public health, and nutrition courses recruited their students to participate in the study. Students that completed the study received extra credit or bonus points as an incentive for participation. The Institutional Review Board at the university at which the study was conducted provided approval of the project.

All potential participants were required to complete a brief screening questionnaire. Students were eligible to participate in the study if they were enrolled in the university and were between the ages of 19 and 29. All eligible participants were emailed a link to an online consent form and the study questionnaire. After the study questionnaire was complete, students scheduled an appointment for a health literacy assessment session. The investigator administered the four health literacy assessments during a single health literacy assessment session. Each session lasted approximately 50 minutes. Written informed consent was obtained before the health literacy assessments were administered.

Twenty students who completed a health literacy assessment session were selected to participate in an in-depth interview. A maximum variation sampling plan was developed to select the interview participants. To order to ensure that the qualitative phase participants were representative of the larger group, the sampling plan was based on gender, race, HPV vaccine status, and intention to obtain the HPV vaccine. Each interview was video recorded and written informed consent was obtained from each participant. Students who completed an interview were given \$20 as compensation for their time.

*Conceptual Framework* The conceptual framework that was used to design the parent study is presented in Figure 1. This diagram illustrates a causal pathway between health literacy and uptake of the HPV vaccine. This conceptual model is an adaptation of Paasche-Orlow and Wolf's<sup>17</sup> causal pathway between limited health literacy and health outcomes. The major constructs in the conceptual model that were assessed during the quantitative phase of the study were: print literacy, aural cancer literacy, numeracy, and

eHealth literacy. The constructs of the conceptual model that were explored during the qualitative phase of the study were the factors in the social cultural environment that influence health literacy.

### *Data Collection*

The online study questionnaire was used to collect data about the participants' demographic characteristics including age, gender, and race/ethnicity. The questionnaire also contained items used to assess the participants' preferred sources of health information, along with several questions about HPV used in a separate analysis apart from the current report.

The S-TOFHLA was used to assess the participants' ability to understand printed health information. The S-TOFHLA has an internal consistency reliability of 0.90.<sup>25</sup> The NVS was used to assess the participants' ability to use numbers related to health information and their ability to make inferences about health information. Previous studies indicated that the NVS has a Cronbach alpha of 0.76.<sup>14</sup> The short version of the CMLT-Listening was used to assess the participants' ability to understand spoken cancer messages. The CMLT-Listening had a Cronbach alpha of 0.85.<sup>26</sup> The eHEALS was used to assess the participants' use of the Internet to find and evaluate health information.<sup>27</sup> Norman and Skinner<sup>27</sup> reported that the eHEALS had high internal consistency (Cronbach's alpha = 0.88).

During the qualitative phase of the study, semi-structured interviews were conducted using an interview guide that consisted of questions based on constructs from the assessment domains of the PEN-3 model<sup>28</sup> which include the positive, existential, and negative perceptions, enablers and nutrices that influence an individual's health

behaviors. The interview guide also contained questions based on the threshold of the constructs included in the operational definition of cancer literacy. Those constructs included aspects of cancer risk, aspects of information, and aspects of treatment.<sup>28,29</sup> In order to assess students' understanding of spoken cancer messages, the teach back method was also used during the interview. During the teach back activities, students were shown two videos about the HPV vaccine, and asked to tell the investigator what each video was about. The accuracy of the students' recount of the information in the videos was evaluated as being accurate, somewhat accurate, and inaccurate.

## **Analytic Methods**

### *Quantitative Methods*

Descriptive statistics were computed to examine the demographic characteristics of the participants. The mean and range of the participants' scores on the S-TOFHLA, the NVS, the CMLT-Listening and the eHEALS were computed. The Statistical Package for Social Science (SPSS) version 21 for Mac was used for the quantitative data analysis.

### *Qualitative Methods*

During the first coding cycle, the data from the interview transcripts was coded using in vivo coding, i.e. using the participants' own words as codes. During the second cycle of coding, the major themes that occurred most frequently across the 20 interviews were identified. A 3x3 table was created to cross tabulate the themes according to the factors in the PEN-3 model's Relationship and Expectations domain (perceptions, enablers, and nurturers) and Cultural Empowerment domain (positive, existential, and negative). To assess the accuracy of the students' responses during the teach-back



activities, the participants' responses were compared to transcripts of the two videos (see Appendix H).

## **Results**

### *Patient recruitment and characteristics*

During the quantitative phase of the study, 189 students of the 320 who registered and were eligible to participate completed a health literacy test session. The quantitative data analysis was based on the 160 students that completed for all four health literacy assessments. The demographic characteristics of the participants are displayed in Table 1. The mean age of the participants in the quantitative phase was 23.9 years old. The majority of the participants (56.9%) were white, and 33.8% were African American. Most of the participants were 3<sup>rd</sup> year undergraduates or higher.

Twenty students who participated in the quantitative phase were selected to participate in the qualitative phase. The students were selected using a maximum variation sampling plan that was based on the students' gender, race and HPV vaccine status or intention. The mean age of the qualitative phase participants was 22.3 years old. Half of the qualitative phase participants were African American and half were white. Fourteen females (seven African American and seven White), and six males (three African American and three White) completed interviews.

### *Print literacy*

The S-TOFHLA was used to assess the students' print literacy. The mean S-TOFHLA score was 35.2 (range: 27 – 36). As indicated in Table 2, all of the participants

in the quantitative phase had an S-TOFHLA score that categorized them as having adequate functional health literacy.

Despite having scored highly on the S-TOFHLA, only a few of the participants interviewed in the qualitative phase indicated that they regularly used printed sources of health information such as pamphlets and magazines. Students who stated that they used these sources said that they read printed health information only when they were in a waiting room. For example, one student stated:

“The only time I ever see pamphlets would be like the doctor's office. And half the time I might like pick it up read it and just put it back down.” (*African American, female, S-TOFHLA score: 36 out of 36*)

The majority of the participants stated that they did not obtain health information from print sources. One of the main reasons for not using print resources was due to a lack of time. For example, one participant stated:

“I used to read magazines when I was in high school, when I had time to do that. So occasionally it had articles about being healthy and how to substitute some things in your diet for things that are better. So I mean I have at a point in my life but I just don't really see magazines.” (*White, female, S-TOFHLA score: 36 out of 36*)

#### *Aural cancer literacy*

The mean score on the CMLT-Listening for students in the quantitative phase of the study was 82% (range: 24% - 96%). Table 2 displays the participants' scores on the CMLT-Listening. Approximately, 68.4% of the participants scored 80% or higher.

During the in-depth interview, students were asked to participate in a teach-back activity that was used to further assess their aural cancer literacy. The students' recount of the information in the videos revealed that several of them had challenges accurately restating the information. The majority of the responses were vague, and lacked precise details. For example, the participant's statement below leaves out the fact that there are 100 strains of HPV, some can lead to cervical cancer and while 1 in 4 women are infected with HPV, not all of them have the strain that can cause cervical cancer:

“That was about the HPV vaccine and now I kinda know what that is. It can cause cervical cancer. But it is very prevalent, like one in four women have it, and that they are going to be testing the vaccine to see if it like made cervical cancer, I think. The rates go down, yeah that is the gist of it.” (*White, female, CMLT-Score: 80%*)

### *Numeracy*

The quantitative participants' mean score on the NVS was 5.1 (range: 1 – 6). As indicated by the data displayed in Table 2, 88% of the participants were categorized as having adequate literacy based on their scores. Several participants were not able to respond to questions that required basic computational skills, and choose not to answer those questions.

Although the CMLT-Listening was developed to assess aural cancer literacy and not numeracy, it should be noted that the most commonly missed questions in that assessment required students to use their numeracy skills. For example, a video that is a part of the CMLT-Listening states “they [experts] estimate that CT scans may cause up to 2% of all cancers today.” The follow-up statement that required students to indicate if it

was the same or different as the video stated “Experts estimate that CAT scans may cause as many as two out of ten of all cancers today.” Approximately 37.3% of the participants responded incorrectly to that item.

Furthermore, the videos that were used during the teach-back activity contained a fair amount of numeric data regarding the prevalence of HPV infections among women and men in the US and the incidence of HPV-related cancers among men and women. Only a few of the students who were interviewed accurately reiterated numeric information that was contained in the videos. For example, when asked to recall the information in the video that stated, “25 million women have HPV... that means 1 in 4 women are infected with HPV,” one student stated:

“Basically, 1 in 4 women can have cervical cancer, and there is 25 million people in the US right now with it.” (*White, Female, CMLT-Score: 84%*)

### *eHealth literacy*

The mean eHEALS score of the participants in the quantitative phase of the study was 80.9% (range: 48% to 100%). This indicates that several students rated their skills for finding and evaluating health information on the Internet as low or marginal.

Students’ responses during the interviews confirmed that many of them did not have adequate skills for searching for and evaluating health information on the Internet. During the interview students were asked to discuss how they searched for health information on the Internet. The majority of the students stated that they relied heavily on one Internet source, WebMD, which is a corporate, for-profit website. Several students

also stated that they use Google's search engine and visited websites that appeared in the search results.

The interview participants also indicated that they did not have adequate skills for evaluating the credibility and trustworthiness of Internet sources of health information. When asked how they determine that WebMD or websites appearing in the Google search results are trustworthy or credible, the majority of the participants stated that they "stay away" from dot-com domains or they look for other sources that corroborate the information on the sites that they choose to visit. Other common responses were that they just "trust" the websites, but do not have "good reasons" for trusting them. For example, one student stated:

"That's a great question. I honestly don't know. I just feel like I can. I guess I don't have a reason. I don't know who writes things on there. It could be just anybody, but I feel like its doctors, I guess maybe the MD in the name. I should probably look into that."  
(*White, male, eHEALS Score 86%*)

### *Social and Cultural Factors Related to Health Literacy*

Ratzan and Parker's<sup>1</sup> definition of health literacy includes the "ability to obtain...basic health information and services needed to make appropriate health decisions." Analysis of the qualitative data indicated that the majority of students rely heavily on their families and healthcare providers when seeking health information and making healthcare decisions. Families, particularly mothers, played influential roles in the students' health behaviors. When asked why they rely on their parents as a primary source of health information, several students stated that a parent, relative, or close family

friend worked in the healthcare field, and they were easy to access. For example, one student stated:

“My brother he's in physical therapy school at Georgia State, so he goes you gotta do this, you gotta do that. My dad he's a medical technologist at Emory. My aunt and uncle are pharmacists and my other aunt she's an RN. So you can't really miss too much cause if you're sick, somebody's there tell ‘you take this’, ‘oh, no I think this would be better.’” (*African American, male*)

Students who did not have family members in the healthcare field, stated that they did not know why they relied on their families when making healthcare decisions. For example, one student stated:

“I usually go to my parents first. I don't know why because my mom is a librarian. My dad works for Apple so they don't really know too much.” (*White, male*)

The majority of the students stated that they feel comfortable seeking health information from their doctors. None of the students the students that obtain health information from their doctors stated that they would have challenges communicating with their healthcare providers. Also, the majority of the participants stated that they trusted the information that was given to them by their doctors, and in most cases, they did not seek additional information after speaking to their provider. For example, when asked if she would discuss different types of health problems with her doctor, one participant stated:

“I've had to change doctors a few times but the one I have recently I am very comfortable with, but she's also a woman so I think um I am more comfortable with same gender doctors so yeah I would be pretty comfortable asking about things like that.” (*African American, female*)

## **Discussion**

The results of the quantitative health literacy assessments suggest that the participants had adequate print literacy, health-related numeracy, eHealth literacy, and aural cancer literacy. However, the results of the qualitative phase suggest that the participants' numeracy, eHealth literacy, and aural cancer literacy skills may be less than adequate. Therefore, quantitative assessments of health literacy may not be able to detect the gaps in some components of health literacy.

Regarding print literacy, the findings of this study are similar to the findings to previous studies that aimed to assess the print literacy of college students. For example, Ickes and Cottrell<sup>30</sup> found that the majority of the college students in their study scored very highly on the TOFHLA. Although data collected during the qualitative phase of this study indicates that most students do not use printed health information in the traditional form (e.g. pamphlets, magazines), it can be argued that successfully reading and understanding internet-based information also requires print health literacy.

The scores on the aural cancer literacy assessment indicate that the majority of the participants have adequate aural cancer literacy skills. Some students had difficulty accurately recalling spoken information in videos used in the teach-back activity. The CMLT-Listening includes both “public messages” and “clinical messages”, the latter

being a simulation of a health care provider speaking to a patient. The videos used during the teach-back activity include one public message video about HPV vaccine use among women that was used in the CMLT-Listening, and one public message video about the health effects of HPV infection in males that was obtained from a national broadcast news channel's website. The lack of accuracy in recalling the information in these videos suggests that people in this age group may not accurately process public health messages.

The in-depth interviews revealed that the majority of the interview participants stated that they obtain health information from their healthcare providers and their families. Prior studies suggest that college students rely heavily on their aural literacy skills when seeking health information. For example, Vader et al.<sup>31</sup> found that college students regard the information received during conversations with health center medical staff, health educators, faculty, and parents as the most believable sources of health information.

The findings of this study are also similar to the findings of previous studies that reported that the eHealth literacy of college students is relatively low.<sup>32-34</sup> For example, in a study aimed at assessing the eHealth literacy skills of college students, Ivanitskaya et al.<sup>33</sup> found that the students' average score on the Research Readiness Self-Assessment-health (an eHealth literacy assessment) was 68%, which indicated that the students had poor eHealth literacy skills. Similarly, Hanik and Stellefson<sup>32</sup> found that undergraduate students that completed the Research Readiness Self-Assessment-health had mean test scores that were very low (39.3% - 50.4%). e-Health literacy requires skills to frame inquiries for Internet searching and making judgments about the trustworthiness of



various sources. These are higher level cognitive tasks than may be required by the other three assessments, especially the TOFHLA. Because of this, it should not be surprising that students do less well on this assessment.

### *Implications*

The results of this study suggest that many college students rely on their aural health literacy skills when they seek health information. The health information that they obtain most often comes from interpersonal communications with trusted sources rather than printed material or media sources. Health communication interventions targeting this population may be effective if they are delivered through trusted sources during healthcare provider visits or other means of interpersonal communications. In addition, most of the participants used the Internet to obtain health information. The participants' lower eHealth literacy scores suggest that there is a need for interventions aimed at improving college students' eHealth literacy.

### *Limitations*

One limitation of this study was the use of a convenience sample of students from one university. All of the students that completed a health literacy test session and an interview were enrolled in health-related courses at the time the study took place. Furthermore, all of the students had a major that was in a public health or healthcare field. Therefore, these students may not be representative of students at other universities, or students with other majors.

When discussing information related to the operational definition of cancer, several students stated that the information that they discussed came from the videos they watched during the administration of the CMLT-Listening. In addition, interviews were conducted during breast cancer awareness month; therefore, some of the information that the students learned about cancer might have come from promotional campaigns that they were exposed to after they had completed the health literacy assessment session but before the in-depth interview. Therefore, maturation bias is a possible limitation of this study.

Although the investigator explained that the information discussed during the interview was confidential, and that the students' instructors would not know who participated in an interview, some students might have responded to interview questions in a socially desirable manner. Also, when being invited to participate in an interview, the students were informed that interview participants would receive \$20 as compensative for their time. This incentive may have caused some students to respond in a socially desirable way.

An additional limitation of this study was the possibility of excessive participant burden experienced during the quantitative health literacy test session. The short version of the CMLT-Listening took 30 minutes to complete, and was administered after the participants had completed three health literacy assessments. Therefore, survey fatigue may have affected the responses of some participants. Finally, 3 of the participants did not complete the assessments in the order in which they were administered to the other participants. It may be possible that this differentially affected their performance on the assessments.

### ***Summary/conclusion***

The students' scores on the quantitative health literacy assessments indicated that they had adequate health literacy. However, further exploration during the qualitative phase revealed that some students had lower eHealth literacy, health-related numeracy and aural cancer literacy skills. Assessing health literacy using a one-dimensional approach may not accurately reflect college students' level of health literacy. Since spoken health information from trusted sources and Internet based health information were the students' primary sources of health information, there is a need to improve college students' eHealth literacy and aural cancer literacy skills. Improving the components of health literacy that are most commonly used by students may have significant effects on their healthcare decision making.

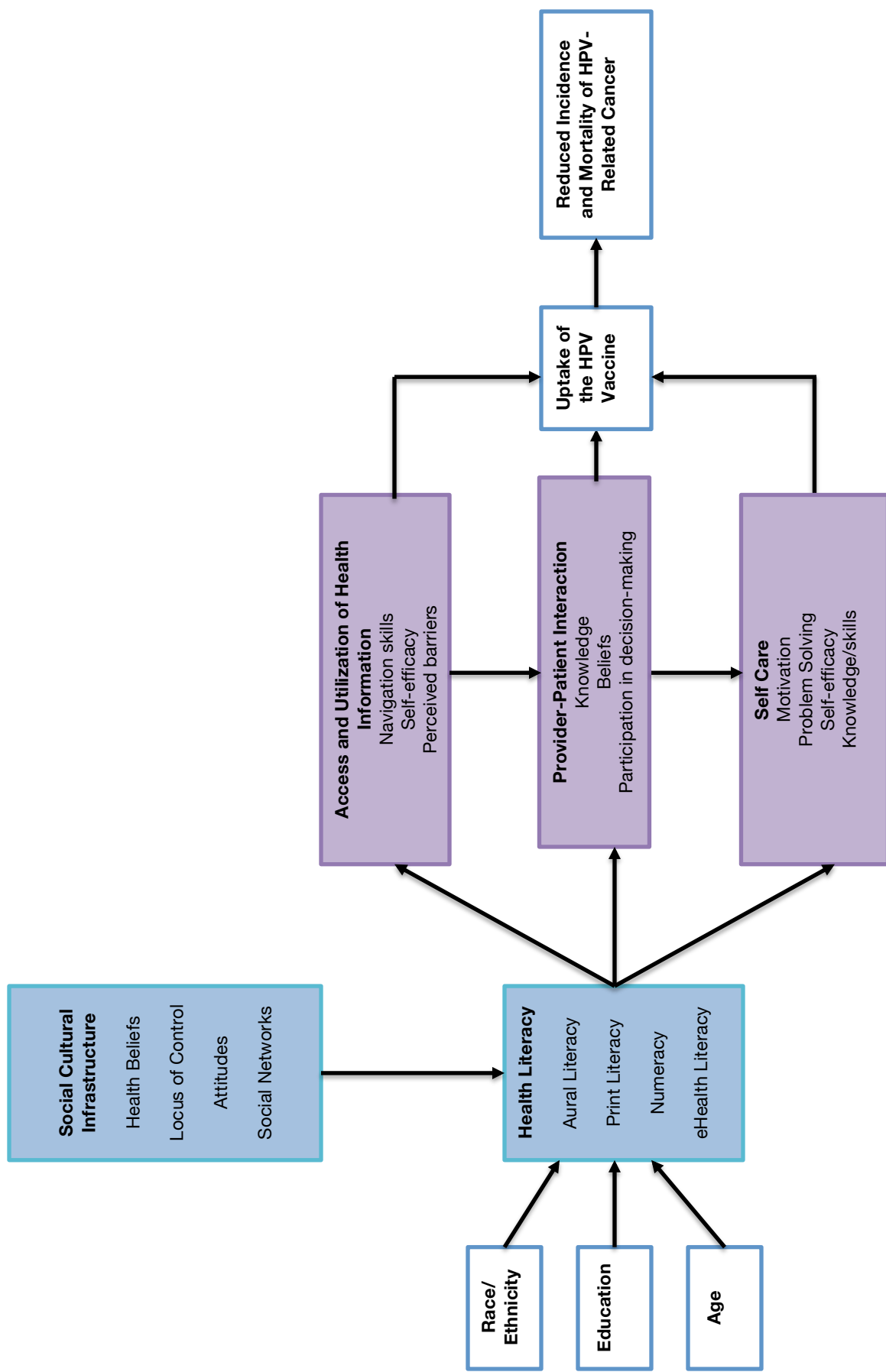


Figure 1. A conceptual model of the influence of health literacy on the uptake of, or intention to obtain, the HPV vaccine. Adapted from Passche-Orlow & Wolf (2007). Causal pathway between limited health literacy and health outcomes.

**Table 1***Participant Characteristics*

Characteristic	Participants n(%)
Age, M(SD)	23.9(6.8)
Gender	
Female	130 (81.3)
Male	29 (18.1)
Transgender	1 (0.6)
Race/Ethnicity	
African American	54 (33.8)
Asian and Pacific Islander	9 (5.6)
Native American	1 (0.6)
Hispanic	2 (1.3)
White	91 (56.9)
Other	4 (2.4)
Year in School	
1st year undergraduate	3 (1.9)
2nd year undergraduate	42 (26.3)
3rd year undergraduate	49 (30.6)
4th year undergraduate	29 (18.1)
5th year or more undergraduate	17 (10.1)
Graduate or professional	18(11.3)

**Table 2***Participants' Health Literacy Assessment*

Health Literacy Assessment	Participants n(%)
<i>S-TOFLHA</i>	23.9(6.8)
Mean (range)	
Adequate Functional Health Literacy (36 - 23)	160(100)
Marginal Functional Health Literacy (22 - 17)	0(0)
Inadequate Functional Health Literacy (16 - 0)	0(0)
<i>Newest Vital Sign</i>	
Adequate literacy (6 - 4)	142(88.8)
Possibility of low literacy (3 - 2)	17(10.6)
High likelihood of limited literacy (1 - 0)	1 (0.6)
<i>Cancer Message Literacy Test-Listening</i>	
100% - 90%	49(30.6)
89% - 80%	62(38.8)
79% - 70%	26(16.3)
69% - 60%	15 (9.4)
59% or below	8(5.0)
<i>eHealth Literacy Scale</i>	
100% - 90%	33(20.6)
89% - 80%	65(40.6)
79% - 70%	44(27.5)
69% - 60%	13(8.1)
59% or below	5(3.1)

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## **Manuscript 2: The Association Between Health Literacy and Uptake of the Human Papillomavirus Vaccine Among College Students**

**Abstract:** The incidence of Human Papillomavirus (HPV) -related cancer in the US is highest among men and women between the ages of 20 to 24. The quadrivalent HPV vaccine can confer protection against the strains HPV that are associated with the development of cervical cancer, head and neck cancer, penile cancer, and anal cancer. The uptake of the HPV vaccine among people between the ages of 18 and 26 are very low. Previous studies have shown that people with adequate health literacy skills are more likely to engage in preventive health behaviors, including uptake of vaccines. We conducted an assessment for four components of health literacy (print literacy, health-related numeracy, aural cancer literacy, and eHealth literacy) with 160 college students. With the exception of eHealth literacy, there were no statistically significant differences between the health literacy test scores of students who had received the HPV vaccine and students who had not received the HPV vaccine.

**Keywords:** health literacy, college students, human papillomavirus vaccine

The incidence and mortality rates of Human Papillomavirus (HPV)-related cancers among men and women in Alabama are higher than the national average (Siegel, Naishadham, & Jemal, 2013). Several types of HPV-related cancers, such as cervical cancer and oropharyngeal cancer, can be prevented by the use of the quadrivalent and bivalent HPV vaccines, which are recommended for males and females between the ages of 9 and 26 (Committee on Infectious Diseases, 2012; Dunne et al., 2011). The incidence of new HPV infections is highest among people between the ages of 20 – 24 (Castellsagué, 2008): approximately, one in four women between the ages of 20 to 24 acquire HPV infections (Brisson, Drolet, & Malagón, 2013). Therefore, uptake of the HPV vaccine among people between the ages of 18 to 26 who had not been vaccinated at younger ages could confer protection for a significant number of individuals.

The Institute of Medicine defines health literacy as the ability to obtain, process, and understand the health information that is needed to make healthcare decisions (Ratzan and Parker, 2000). People with inadequate health literacy are significantly more likely to experience difficulty navigating the healthcare system and adverse health outcomes (Cho, Lee, Arozullah, & Crittenden, 2008; DeWalt et al., 2004; Lindau et al., 2002; Shieh & Halstead, 2009). Higher levels of health literacy have been associated with engagement in preventive health behaviors, including uptake of vaccines (Baker, Parker, Williams, & Clark, 1998; DeWalt, Berkman, Sheridan, Lohr, & Pignone, 2004; Ratzan, 2011; Schillinger et al., 2002). For example, a study by Berkman et al. (2004) found that people with low health literacy were less likely to obtain the flu vaccine (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011 ). In addition, low health literacy has been associated with a lack of knowledge about vaccine-preventable diseases

such as cervical cancer (Davis, Williams, Marin, Parker, & Glass, 2002; Lindau et al., 2002; Rogers, Wallace, & Weiss, 2006).

Initial research suggested that the HPV vaccine was most effective in children who had never been exposed to HPV (Markowitz et al., 2007). Therefore, the majority of studies regarding uptake of the HPV vaccine have focused on parents' decision to obtain the HPV vaccine for their children (Constantine & Jerman, 2007; Dempsey, Butchart, Singer, Clark, & Davis, 2011; Sanders Thompson, Arnold, & Notaro, 2012; St John, Pitts, & Tufts, 2010). However, more recent studies have shown the HPV vaccines are effective in people who have been previously exposed to multiple strains of HPV (Dunne et al., 2011; McKeage & Romanowski, 2011; Paavonen et al., 2009; Schiller, Castellsagué, & Garland, 2012). Emerging adults, people between the age of 18 and 29, including those who have initiated sexual activity, have the ability to make healthcare decisions on their own, such as whether or not to obtain the HPV vaccine (Arnett, 2000). Studies are needed that investigate the factors that influence the decision to obtain the HPV vaccine among emerging adults up to age 26. Given its relationship to other vaccination behaviors (Bennett, Chen, Soroui, & White, 2009; Howard, Sentell, & Gazmararian, 2006; Sudore et al., 2006; White, Chen, & Atchison, 2008), health literacy is a good candidate for study as a determinant of HPV vaccine uptake. Thus, there is a need to investigate the relationship between health literacy and uptake of the HPV vaccine among emerging adults.

We conducted an investigation to determine whether different types of health literacy are associated with uptake of the HPV vaccine among emerging adults enrolled

at a university. Four tools were used to assess the participants' print literacy, health-related numeracy, aural cancer literacy, and eHealth literacy.

## **Methods**

### *Participant selection*

The study took place at a large urban university in the Southeast. The study was approved by the Institutional Review Board at the University of Alabama at Birmingham.

Students were recruited over a period of two semesters. Course instructors offered extra credit or bonus points as an incentive for participation in the study. Students were provided with an alternative option for the extra credit if they chose not to participate in the study or were not eligible to participate in the study.

Potential participants completed a brief screening questionnaire that allowed the investigator to determine their eligibility. Students were eligible to participate in the study if they were enrolled as a student at the university, and were between the ages of 19 and 29. Eligible students completed a study questionnaire that was administered via the Internet. The study questionnaire was used to collect demographic information, including race/ethnicity and gender, having ever had sex, HPV vaccine history, and HPV knowledge.

### *Variables and procedures*

After completing the online informed consent form and the study questionnaire, participants scheduled an appointment to complete a health literacy test session. Before the health literacy assessments were administered, the investigator reviewed the informed consent form with the participants and obtained written informed consent. During the

health literacy test session, participants completed four health literacy tests, the Short Test of Functional Health Literacy in Adults (S-TOFHLA) (Parker, Baker, Williams, & Nurss, 1995), the Newest Vital Sign (NVS) (Weiss et al., 2005), the eHealth Literacy Scale (eHEALS) (Norman & Skinner, 2006), and a short form of the Cancer Message Literacy Test –Listening (CMLT-Listening) (Mazor et al., 2012). It took the participants approximately 50 minutes to complete all four-health literacy assessments. The investigator conducted all assessments.

The S-TOFHLA was used to assess the participants' ability to understand printed health information. In an early analysis of internal consistency, the S-TOFHLA demonstrated a 0.90 Cronbach alpha coefficient (Parker et al., 1995). The NVS was used to assess the participants' ability to use numbers related to health information and their ability to make inferences about health information (numeracy). Weiss et al. (2005) reported a Cronbach alpha of 0.76 for their administration of the NVS. The CMLT-Listening was used to assess the participants' ability to understand spoken cancer messages (aural cancer literacy). The CMLT-Listening demonstrated a Cronbach alpha of 0.85 (Mazor et al., 2012). The eHEALS was used to assess the participants' perceptions of their ability to use the Internet to find and evaluate health information (Norman & Skinner, 2006). Norman and Skinner (2006) reported that the eHEALS showed high internal consistency (Cronbach's alpha = 0.88).

HPV vaccine uptake was assessed by an item on the study questionnaire which asked "Have you ever had the HPV vaccine (Gardasil® or Cervarix®)?" Participants were also asked to indicate why they had obtained the HPV vaccine. Response options for this question included "I am worried I might get an HPV-related cancer," "I am worried I

might get HPV,” “I am worried I might get genital warts,” “My healthcare provider recommended it to me,” “Someone close to me had an HPV-related cancer,” “Other reason(s),” and “Do not know.”

### *HPV Knowledge*

A scale consisting of 15 items developed by the Katz et al. (2011) was used to assess the participants’ knowledge of HPV. The 15 items were true or false questions focused on basic facts about HPV including items such as “HPV may be spread from person to person through oral sex,” “HPV infection among women is rare,” and “HPV can cause cancer of the penis.”

### *Analytic methods*

Descriptive statistics were calculated to summarize the demographic characteristics of the participants and their HPV vaccine uptake. Four independent samples t-tests were used to determine whether there was a difference in the mean health literacy assessment score for students who received the HPV vaccine and students who did not receive the HPV vaccine. Where significant differences were found, a logistic regression model was tested using vaccine status as the dependent variable and the health literacy assessment as the independent variable, controlling for relevant demographics (e.g. race) and knowledge. SPSS 21.0 for Mac (SPSS Inc., Chicago, IL) was for the data analysis.

## Results

### *Participant characteristics*

Students were recruited during the summer and fall semesters of 2013. Figure 1 displays the consort diagram of participant enrollment and participation. Of the students who registered ( $n = 344$ ), 320 were eligible to participate in the study, and 253 of these completed a study questionnaire. Health literacy test sessions were completed by 189 students. Due to incomplete test data among the 189, the data from 160 students were used in this analysis. There were no differences between the students who did not attend a health literacy test session and those who did.

As shown in Table 1, the majority of the participants were female (81.3%). Approximately 56.9% of the participants were white and 33.8% were African American. Undergraduate students in their third year made up that largest proportion (30.6%) of the participants, followed by undergraduates in their second year (26.3%). The mean age of the participants was 23.4 years old. HPV vaccine uptake was reported by 40% of the respondents. More than half (55%) of the participants who obtained the vaccine completed the three dose series.

Mean scores on the health literacy assessments were 35.18 for STOFHLA ( $SD = 1.15$ ; range 27 - 36); 20.49 for CMLT ( $SD = 3.05$  range 6 - 24); 5.08 for NVS ( $SD = 1.16$ ; range 1 - 6); and 40.43 eHEALS ( $SD = 5.15$ ; range 24 - 50). Mean scores for all assessments were near the high end of the range of scores.

### *Health literacy and HPV vaccine uptake*

The results of the t-tests that were conducted to assess the difference between the health literacy assessment scores of vaccinated students and unvaccinated students are displayed in Table 2.



### *Print Literacy*

An independent samples t-test was conducted to compare the S-TOFHLA scores for students who received and students who had not received the HPV vaccine. As seen in Table 1, there was no significant difference in the S-TOFHLA scores for vaccinated students ( $M = 35.36$ ,  $SD = .76$ ) and unvaccinated students ( $M = 35.05$ ,  $SD = 1.34$ );  $t(158) = 1.66$ ,  $p = .099$  (two-tailed). The magnitude of the differences in the means (mean difference = .31, 95% CI: -.06 to .67) was small (eta squared = .017).

### *Aural Cancer Literacy*

An independent samples t-test was conducted to compare the CMLT-Listening scores of vaccinated and unvaccinated students. There was no significant difference in the CMLT-Listening scores for vaccinated students ( $M = 20.73$ ,  $SD = 2.64$ ) and unvaccinated students ( $M = 20.32$ ,  $SD = 3.29$ );  $t(158) = .84$ ,  $p = .404$  (two-tailed). The magnitude of the difference in the means (mean difference = .41, 95% CI: -.56 to 1.38) was very small (eta squared = .004).

### *Health-Related Numeracy*

An independent samples t-test was conducted to compare the NVS scores of vaccinated and unvaccinated students. There was no significant difference in the NVS scores for vaccinated students ( $M = 5.16$ ,  $SD = .98$ ) and unvaccinated students ( $M = 5.03$ ,  $SD = 1.26$ );  $t(158) = .670$ ,  $p = .504$  (two-tailed). The magnitude of the difference in the means (mean difference = 1.25, 95% CI: -2.44 to 4.94) was very small (eta squared = .002).

### *eHealth Literacy*

An independent samples t-test was conducted to compare the eHEALS scores of vaccinated and unvaccinated students. There was a significant difference in the eHEALS scores for vaccinated students ( $M = 39.34$ ,  $SD = 5.37$ ) and unvaccinated students ( $M = 41.15$ ,  $SD = 4.90$ );  $t(158) = -2.19$ ,  $p = .030$  (two-tailed). The magnitude of the difference in the means (mean difference =  $-1.80$ , 95% CI:  $-3.42$  to  $-1.80$ ) was small (eta squared =  $.03$ ), and the difference was not in the expected direction; the unvaccinated participants scored slightly higher than those vaccinated.

### *Logistic Regression*

Direct logistic regression was performed to investigate the association between the students' scores on the eHEALS and uptake of the HPV vaccine. Previous studies have shown that factors associated with HPV vaccine uptake include history of sexual activity, race, and knowledge of HPV (Brewer & Fazekas, 2007; Cates, Brewer, Fazekas, Mitchell, & Smith, 2009; Jones & Cook, 2008; Patel et al., 2012). Therefore, the regression model included four independent variables (eHEALS score, Ever had sex, race, and HPV knowledge score). The full model containing all of the predictor variables was statistically significant,  $X^2(4, N=160) = 10.289$ ,  $p = .036$ , indicating that the model as a whole was able to distinguish between students who reported getting the HPV vaccine and those who reported that they did not get the HPV vaccine.

The data displayed in Table 2 show that the eHEALS score and race made unique, statistically significant contributions to the model. For African American students, the probability of obtaining the HPV vaccine was  $.445$ . The eHEALS score was the

strongest predictor of HPV vaccine uptake with an odds ratio of .93. This indicated that for every additional 1-point increase in eHEALS score, the odds of students obtaining the HPV vaccine go down .

## **Discussion**

This is the first study to assess the association between health literacy and uptake of the HPV vaccine among college students. The results of independent samples t-tests indicated that scores from the S-TOFHLA, the NVS, and the CMLT-Listening were not statistically significantly different between vaccinated and unvaccinated students. Scores on the eHEALS were found to be statistically significantly different, therefore logistic regression was performed on a model including eHEALS score, race, HPV knowledge score, and ever had sex. The regression analysis indicated that scores on the eHEALS, and race were the only variables that made statistically significant contributions to the model. The score on the eHEALS was found to be the strongest predictor of HPV vaccine uptake, indicating that unvaccinated students scored higher on the eHEALS than vaccinated students. This finding is opposite of our expectation that students with higher health literacy scores would be more likely to have had the HPV vaccine.

We found that the odds of African American students getting the HPV vaccine were .445. These results contradict national data regarding the uptake of the HPV vaccine among African Americans. For example, data from the National Teen Immunization Survey indicates that African American girls and boys have a higher rate of vaccine initiation than their white counterparts (Laz, Rahman, & Berenson, 2012) This discrepancy may be the result of the older age in the college sample. The mean age in the

NTIS was 14.86 while for this study the mean age was 23.4 years (Centers for Disease Control and Prevention, 2011). Further, within this study the difference between the percent of white student and African American students that reported being vaccinated may reflect the earlier time period when these students were initially eligible for the vaccine. A college sophomore is typically around 19 years old, and would have been eligible for the vaccine as many as eight years ago. When the vaccine was first made available for the public, white children and adolescents were more likely to be vaccinated than their African American counterparts.

Scores on the HPV knowledge scale revealed that the majority of the participants had little knowledge of HPV. There were no significant differences between the HPV knowledge scores of vaccinated and unvaccinated participants. Among vaccinated participants, a recommendation for the HPV vaccine from a healthcare provider was the most common reason for obtaining the vaccine.

To the best of our knowledge, there are no published studies regarding health literacy and uptake of the HPV vaccine. Unlike in previous studies of print health literacy and uptake of other types of vaccines, the health literacy tests scores for three components of health literacy of the participants in this study were not associated with uptake of the HPV vaccine (Bennett et al., 2009; Howard et al., 2006; Sudore et al., 2006; White et al., 2008). One of the main differences between this study and studies of health literacy and other types of vaccine uptake is that all of the participants in this study were enrolled in college. The education level of participants in other vaccine studies varied since the samples were more representative of the US population. In addition, the participants in this study were significantly younger than the participants of other studies.

For example, the mean age of the participants in the study conducted by Sudore et al. (2006), which examined the association between scores on the Rapid Estimate of Adult Literacy in Medicine and uptake of the flu vaccine, was 75.6. The current study's more restricted sample in terms of age and education resulted in relatively high scores on all assessments with small magnitudes of differences in scores between those who were and were not vaccinated.

Similar to the findings of this study, previous studies have shown that HPV vaccine uptake is associated with recommendations from health care providers (Ylitalo, Lee, & Mehta, 2013). The majority of the vaccinated students who responded to a question about the reason that they obtained the vaccine indicated that a healthcare provider had recommended it. This is consistent with studies that found that the most significant predictor of parents' decision to seek the HPV vaccine for their child was a doctor's recommendation (Brewer & Fazekas, 2007; Conroy et al., 2009; Zimet et al., 2005).

A limitation of this study was the use of the HPV knowledge scale that was developed by Katz et al. (2011). Katz and his colleagues (2011) did not report the reliability of the scale. A post hoc analysis of the HPV knowledge scale was performed with the data that was collected during this study. The reliability of the scale was extremely low (Cronbach alpha = .32). One factor that may have caused the reliability of the scale to be so low with this sample was that Katz and his colleagues developed the scale to assess the HPV knowledge of college age males. In this study, we used the scale to assess HPV knowledge of college age males and females.

### *Implications*

The results of this study suggest that health literacy did not play a role among college students in the uptake of the HPV vaccine. These results are consistent with the findings in the qualitative phase of the study (Williams et al, in preparation), which suggests that these emerging adults may be relying on their healthcare providers and parents to suggest preventive measures, such as vaccines, rather than seeking information and making autonomous healthcare decisions.

In addition, these results call for an increase in interventions aimed at increasing emerging adult's uptake of the HPV vaccine. When the quadrivalent HPV vaccine was first released, the majority of promotional messages were targeted towards teens and the parents of children and adolescents (Calloway, Jorgensen, Saraiya, & Tsui, 2006). Since emerging adults have the ability to make their own health care decisions, more educational messages need to be targeted towards this population.

The results of the health literacy test scores indicate that overall, college students have adequate functional health literacy skills. Therefore, they may be better able to process and act upon HPV prevention messages that are delivered via various channels.

### *Limitations*

The use of a convenience sample of students from one university is one limitation of this study. Since all of the participants were enrolled at one university, the results of this study may not be generalizable to all college students in the Southeastern US. In addition, recruitment occurred through professors who were teaching health-related courses and the majority of the participants had a major that was public health or

healthcare related (i.e. pre-nursing). Therefore, the students who participated in this study may not be representative of students enrolled in non-health related courses or who have a major in non-health related field. Furthermore, students were recruited to participate in the study by their professors, hence social desirability bias may have affected the manner in which the participants responded to the questions on the questionnaire.

Also, students who completed the study questionnaire may not have accurately recalled whether or not they obtained the HPV vaccine, since some students may have been vaccinated up to five years ago. Some students may also have received the vaccine without being informed of what they were receiving. Therefore, the possibility of recall bias is a limitation of this study.

Another limitation of this study was the low return rate. There was attrition of eligible students during the different stages of the study. Of the 320 eligible students that registered, 79% completed the online study questionnaire, and only 59% completed a health literacy test session. It is possible that the students who dropped out before completing a health literacy test session were different from those students who completed all of the stages of the study.

Another limitation of the study was the measures that were used to assess the participant's print literacy, health-related numeracy and HPV knowledge. The S-TOFHLA is relatively easy to read, and may not have been a true measure of the participants' ability to understand printed health information. In addition, when the NVS was administered, several participants asked for questions to be read multiple times. Since this assessment was not timed, the time it took students to complete NVS varied, however, that is not reflected in their scores. Further, for all four assessments

participants' mean scores were close to the top of the possible range, indicating little room for between-group differences. The Cronbach's alpha of the 15-item scale that was used to assess participants' knowledge of HPV was very low, which suggests that it may not have been a reliable measure.

### *Conclusion*

Scores on three of four health literacy assessments of vaccinated and unvaccinated students were not statistically significantly different. Therefore, health literacy may not be associated with uptake of the HPV vaccine within this population. The most common reason for obtaining the HPV vaccine was a recommendation from a healthcare provider. Emerging adults may be making decisions about the HPV vaccine based on information that they receive from trusted sources of health information rather than using their health literacy skills to make decisions about HPV vaccine uptake.



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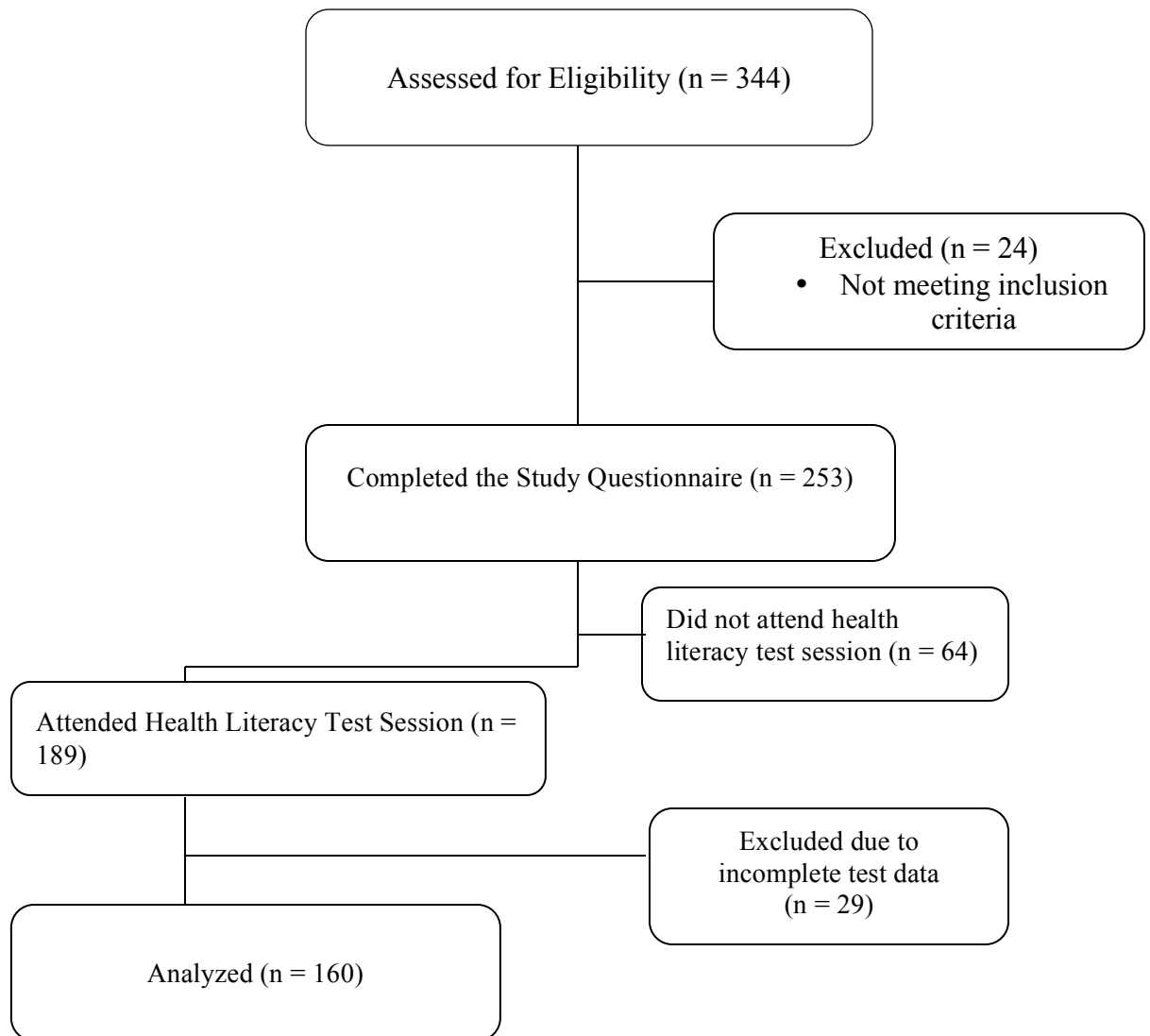
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**Table 1***Participant Characteristics*

Characteristic	Participants n(%)	Ever Received the HPV Vaccine	
		Yes (n = 64)	No (n = 96)
Age, M(SD)	23.9	20.8(25.8)	25.8(8.0)
Gender			
Female	130 (81.3)	63(98.4)	67(69.8)
Male	29 (18.1)	1(1.6)	28(29.2)
Transgender	1 (0.6)	0(0)	1(1.0)
Race/Ethnicity			
African American	54 (33.8)	16(25.0)	38(39.6)
Asian and Pacific Islander	9 (5.6)	2(3.1)	7(7.3)
Native American	1 (0.6)	0(0)	1(1.0)
Hispanic	2 (1.3)	1(1.6)	1(1.0)
White	91 (56.9)	43(67.2)	48(50.0)
Other	4 (2.4)	2(3.1)	1(1.0)
Year in School			
1st year undergraduate	3 (1.9)	0	3(3.1)
2nd year undergraduate	42 (26.3)	23(35.9)	19(19.8)
3rd year undergraduate	49 (30.6)	25(39.1)	24(25.0)
4th year undergraduate	29 (18.1)	10(15.3)	19(20.2)
5th year or more undergraduate	15 (9.4)	4(6.3)	11(11.5)
Graduate or professional	18(11.3)	2(3.1)	16(16.7)
Health Literacy Test Scores, M(SD)			
CMLT-Listening	20.5(3.0)	20.7(2.6)	20.3(3.3)
eHEALS	40.4(5.2)	39.3(5.4)	41.2(4.9)
S-TOFHLA	35.2(1.2)	35.4(.8)	35.1(1.3)
NVS	5.1(1.2)	5.2(1.0)	5.0(1.3)
Ever Had Sex			
Yes	125(78.1)	58(90.6)	67(69.8)
No	35(21.9)	6(9.4)	29(30.2)
Ever Received the HPV Vaccine			
Yes	64 (40.0)		
No	96 (60.0)		

Figure 1

Consort diagram of participant enrollment and participants in the study





**Table 2**

Health Literacy Test Scores by HPV Vaccine Uptake Status (n = 160)

Variables	Vaccinated Students ( n = 64)			Unvaccinated Students ( n = 96)			<i>t</i>	<i>p</i>
	<i>M</i>	( <i>SD</i> )	<i>Range</i>	<i>M</i>	( <i>SD</i> )	<i>Range</i>		
S-TOFHLA Score	35.36	(.76)	34 – 36	35.05	(1.34)	27 - 36	1.662	.099
CMLT- Listening Score	20.73	(2.64)	13 – 24	20.32	(3.29)	6 - 24	.836	.404
eHEALS Score	39.34	(5.37)	28 - 49	41.15	(4.90)	24 - 50	- 2.194	.030
NVS Score	5.16	(.98)	2 - 6	5.03	(1.26)	2 - 6	.670	.504

**Table 3***Logistic Regression Predicting Likelihood of Reporting Obtaining the HPV**Vaccine*

	B	S.E.	Wald	<i>p</i>	Odds Ratio	CI
eHEALS Score	-.08	.03	5.22	.022	.93	.87 - .99
Race	-.81	.38	4.50	.034	.45	.21 - .94
HPV Knowledge Score	-.04	.18	.12	.74	.96	.76 - 1.21
Ever had sex	-.29	.42	.50	.48	.75	.33 - 1.69
Constant	3.40	1.91	3.18	.075	30.01	

### **Manuscript 3: A mixed methods assessment of the cancer literacy of emerging adult college students**

#### **Abstract**

During the last decade, the incidence of some types of cancer related to the Human Papillomavirus (HPV) have increased among men and women in the US. HPV is the most common viral sexually transmitted infection in the US. The prevalence of HPV is highest among people between the ages of 20 to 24 years. Cancer literacy can affect an individual's ability to process and act on cancer prevention messages, such as messages promoting the HPV vaccine. The purpose of this study was to assess the cancer literacy of college students. A sequential explanatory mixed methods research design was used to assess college students' health literacy using quantitative and qualitative methods. During the quantitative phase, students completed the Cancer Message Literacy Test-Listening (CMLT-Listening), which was developed to assess aural cancer literacy skills. During the qualitative phase, in-depth interviews were conducted with a subset of the quantitative phase participants to further assess the students' aural cancer literacy skills and the knowledge of three aspects of cancer. The mean CMLT-Listening score of the 160 students that completed the assessment was 21.45 (maximum possible score: 25). The CMLT-Listening scores indicated that the majority of the students had adequate cancer literacy skills. However, the results of the qualitative phase indicate that many students do not possess knowledge of aspects of cancer that some experts believe laypeople should know. The results of this study indicate that there is a need for interventions aimed at increasing the cancer literacy of college students.

**Keywords:** health literacy, cancer literacy, college students

## 1. Introduction

Cancer is the leading cause of death among people 40 to 79 years old in the United States (US) [1]. Although the overall cancer incidence rate among men in the US has been declining, the cancer incidence rate among women has remained stable [1,2]. For example, among women there has been a lag in the decline of lung cancer incidence and breast cancer incidence rates have stabilized [2–4]. Furthermore, there has been an increase in the incidence of some types of cancers among men and women, including melanoma and human papillomavirus-positive oropharyngeal cancer [1,2].

Several of the types of cancers that have an increased incidence rate are associated with behavioral risk factors, such as the use of tobacco and exposure to UV radiation [2,3,5]. People with limited health literacy are less likely to perceive the risks of cancer promoting behaviors and less likely to engage in cancer preventive behaviors [6–16]. An individual's cancer literacy can affect their ability to access and use healthcare, their interaction with healthcare providers, and their engagement in self-care behaviors [7,17–20]. Diviani and Schulz suggest that cancer literacy includes, “all of the knowledge a layperson needs to possess to understand the information and advice the health system has to offer with regard to preventing, diagnosing, and treating cancer” [21].

Emerging adults, people between 18 and 29-years old, engage in behaviors that could affect their risk of developing certain types of cancer later in life [22]. For example, the quadrivalent human papillomavirus (HPV) vaccine is recommend for females and males up to the age of 26 for the prevention of HPV-related cancers; and this is the age range in which women should initiate cervical cancer screenings [23–25]. The majority

of health literacy research has focused on the health literacy of older adults. However, there is a benefit to increasing the cancer literacy of emerging adults since it could lead to an increased adherence to cancer prevention and control recommendations and a subsequently reduction in cancer incidence and mortality [26,27].

The purpose of this mixed methods study was to assess emerging adult college students' cancer literacy. The Cancer Message Literacy Test-Listening (CMLT-Listening) was used to assess students' aural cancer literacy skills and semi-structured, in-depth interviews were conducted in order to develop a deeper understanding of the students' cancer literacy.

## **2. Methods**

### *2.1 Participant selection*

Students at a midsize urban university in the Southeast were recruited to participate in the study through course instructors. Potential participants completed a brief screening questionnaire online that was used to assess their eligibility. Students were deemed eligible to participate in the study if they were enrolled as a student at the university and were between the ages of 19 and 29. The eligible students were asked to complete an informed consent form and the study questionnaire online.

The parent study was a sequential, explanatory mixed methods study aimed at comprehensively assessing college students' health literacy. The study was conducted in two phases. The first phase was the quantitative phase, during which the students completed assessments of their print health literacy, health numeracy, eHealth literacy, and aural cancer literacy. During the second phase of the study, a subset of the phase one

participants completed an in-depth interview. The study occurred between June and October 2013.

## *2.2 Quantitative assessment of cancer literacy*

The CMLT-Listening was developed to assess an individual's ability to understand spoken messages about cancer, cancer prevention, and cancer screening (aural cancer literacy) [28]. The short version of the CMLT-Listening that was used for this study consisted of 8 brief videos and 2 radio announcements about various aspects of HPV, cervical cancer, breast cancer, colon cancer, prostate cancer, and skin cancer. Either 2 or 3 statements followed each video or radio announcement. The participants were asked to determine if the information in the statements that followed each video was the same as or different from the information that was in the video. Possible scores on the short CMLT-Listening range from 0 – 25. The short CMLT-Listening has been shown to have good reliability (Cronbach's  $\alpha = 0.85$ ) [29]. The full CMLT-Listening is correlated with the Rapid Estimate of Adult Literacy in Medicine (REALM), the risk items from the Lipkus numeracy test, and self-reported reading ability [30].

## *2.3 Qualitative assessment of cancer literacy*

During the qualitative phase, twenty students that participated in the quantitative phase were invited to participate in an individual, in-depth interview. A maximum variation sampling plan based on gender and ethnicity ? was used to select the participants for the qualitative phase. The principal investigator conducted each interview in a private room. Each interview was video and audio recorded.

Questions based on three of the key components of Diviani and Schulz's operational definition of cancer literacy were included in the semi-structured interview guide. Table 1 contains a description of the constructs that were used in the interview [21]. For example, questions regarding the Aspects of Cancer Risk included: "Do you have control over whether you get cancer?" and "What causes cancer?" Questions used to elicit information about the participants' sources of health information, methods of validating the health information that they use, and knowledge of cancer screening (Aspects of Information) included: "The last time you needed health information, where did you go?" and "How do you determine that the information is valid?" An example of a question used to gather information about the participants' knowledge of cancer treatment is: "What types of cancer treatment are you familiar with?"

#### *2.4 Quantitative data analysis*

Descriptive statistics were computed to summarize the demographic characteristics of the participants. The mean of the participants' CMLT-Listening score was computed. The Statistical Package for Social Science (SPSS) version 21 for Mac was used for the quantitative data analysis.

#### *2.5 Qualitative data analysis*

The recording of each interview was transcribed. The qualitative data in the transcripts were analyzed during two cycles of coding. An in-vivo coding method was used during the first coding cycle to code the data using the participants' exact words. During the second cycle of coding, a focused coding method was used. In focused

coding, the data the codes from the first coding cycle are organized into themes. The in-vivo codes were categorized according to the three constructs and their sub-constructs of the operational definition of cancer literacy used in the interview guide.

### **3. Results**

#### *3.1 Participant recruitment and characteristics*

As noted earlier, the parent study included 160 students who completed the CMLT-Listening along with other health literacy assessments. For the analysis reported here, twenty students that participated in phase one were asked to participate in phase two, the qualitative phase of the study. Results are limited to the 20 students who participated in both phases of the study. The characteristics of the 20 participants are displayed in Table 1. In addition, it should be noted that the majority of the participants were recruited from health related courses.

The mean age of the participants was 22.3 years and the majority of the participants were female (70%). Phase two participants did not differ significantly on these characteristics from the phase one participants.

#### *3.2 Aural Cancer Literacy Test*

The mean CMLT-Listening scores of the phase two participants ( $n = 20$ ) was 21.45 out of a possible 25 points (about 86% correct). Overall, the students' scores indicated that they had adequate aural cancer literacy skills.

The most frequently missed item on the CMLT-Listening was "Experts estimate that CAT scans may cause as many as two out of ten of all cancers today." This question was missed by 42% of the participants. This question followed a video showing



computed tomography (CAT) scans and cancer risk. In the video, the narrator stated, “they estimate that CAT scans may cause up to 2% of all cancers today.” Therefore, the narrative in the video did not support the statement.

### *3.3 Qualitative Phase Results*

#### *3.3.1 General Cancer Literacy*

The goals of the qualitative interviews was to provide either corroborating or contradictory evidence of students’ cancer literacy in addition to other components of health literacy. Interview questions, were based on the constructs and subconstructs of the conceptual definition cancer literacy developed by Diviani and Schulz [21].

*General Cancer Knowledge* When asked to define cancer, many students provided a vague, but accurate description of cancer as, “unregulated reproduction of cells” or “cells that go haywire.” Several students did not provide accurate descriptions of cancer. For example, one student stated, “It’s just cells that attack and kill your t-cells.”

The students were also asked to describe what they thought about when they heard the word cancer. All of the students had negative connotations of cancer. Several students viewed cancer as “scary” or their “biggest fear in life.” Several students who had family members with cancer indicated that they had “negative vibes” about cancer because they believed that people with cancer “don’t have good survival rates.”

*Aspects of Cancer Risk.* Several participants were not aware of the risk factors for cancer and the majority of the students did not associate behavioral risk factors with the development of cancer. For example, when asked to describe the risks for getting cancer,

one student stated, “it could be hereditary,...I'm not really sure.” When students did mention individual behavioral risk factors for cancer, the majority of them identified smoking as a risk factor for lung cancer. The following statement illustrates this, “smoking could lead to lung cancer, even secondhand smoke.”

Only a few students were aware that other behavioral factors, such as “eating the vegetables” and “eat a lot of good fiber,” could reduce the risk of cancer. Other cancer preventive behaviors such as regular exercise, limiting alcohol consumption, and maintaining a healthy bodyweight were mentioned infrequently across the interviews.

A few students discussed environmental risk factors associated with cancer. Some were accurate in their beliefs that exposure to the sun could increase the risk of skin cancer. For example, one student discussed his increased risk for skin cancer, “I have red hair, every time I go to the dermatologist they are warning my about skin cancer; tell me to wear sunscreen.” A few students held somewhat accurate beliefs about environmental risks for cancer, yet they were not confident in their knowledge. This statement is an example of an uncertain, but accurate belief about eating processed foods, which have been shown to effect the risk of cancer: “... um, you know we eat so many processed foods now and I don't know if there is a direct connection between that.”

A family history of cancer and/or heredity was commonly mentioned as a cancer risk factor. Regardless of a personal family history of cancer, many students held the belief that they did not have control over whether or not they developed cancer. For example, one student with a family history of cancer stated, “I think that I have control over how early it is caught but do feel like there might be a hereditary aspect to my family's history with breast cancer specifically.”

*Aspects of Information.* Diviani and Schulz's definition of cancer literacy includes the trustworthiness of sources of cancer information as a sub-construct of Aspects of Information [21]. When discussing their common sources of health information nearly all of the participants stated that their main sources of information were the Internet, specifically the WebMD website, their healthcare provider, and their parents. The majority of the participants did not have a valid way of assessing the trustworthiness of information from that they got from the Internet. They assessed trustworthiness according to the site's domain name, for example, "I would like stay away from .coms" or they, "kinda figure they [website authors] hopefully will know what they are talking about." Some participants who had parents who were doctors or nurses felt that they could trust the health information their parents provided because of their professions. However, students who had parents that were not healthcare professionals also viewed them as trustworthy sources. For example, one student stated, "I usually go to my parents first. I don't know why because my mom is a librarian. My dad works for Apple so they don't really know too much." Furthermore, several students indicated that they do not trust information from the media because they "don't think you can trust the media too much."

Diviani and Schulz [21] include knowledge about cancer screening under Aspects of Information (Table 1). During the CMLT-Listening the students were required to watch videos about colonoscopy, prostate specific antigen testing, Pap testing, skin cancer screening, and mammogram. However, when asked to discuss the types of cancer screening that they are familiar with during the in-depth interview, several of the participants indicated that they were, for example, "not too sure about what exact types

of screening.” The majority of the students with some awareness of cancer screenings indicated that the mammogram and the colonoscopy were the types of cancer screenings that they were most aware of. For example, one participant stated, “...probably the breast cancer one and the colonoscopy one are the ones that I am most familiar with because you...hear about it a lot.”

Early detection was the only benefit of screening that was discussed by the participants. Most students who were familiar with at least one type of cancer screening knew that early detection could lead to better outcomes. For example, one student stated that early detection was, “just being able to find it at a place that you would be able to take care of that cancer site without it spreading.”

*Aspects of Treatment* Overall, the majority of students stated that chemotherapy was the type of cancer treatment that they were familiar with. However, many students believed that chemotherapy was the type of treatment that was provided as a last option. For example, one student regarded chemotherapy as the “kind of like the end of the list.” Students infrequently mentioned other types of cancer treatment such as surgery and radiation.

#### **4. Discussion and conclusion**

##### *4.1 Discussion*

The mean CMLT-Listening score of the participants suggested that they had at least adequate cancer literacy. However, the data from the in-depth interviews suggests that many of the participants did not have an adequate understanding of several aspects of

cancer that are considered to be important for laypersons to know, such as the screening tests recommended for most adults and the rationale for early detection.

Very few students were able to provide a detailed definition of cancer. Most students who accurately defined cancer described it as uncontrollable cell growth, but were not aware of many of the risk factors that could lead to the development of cancer.

*Aspects of Cancer Risk.* The participants in this study were most familiar with the behavioral and environmental risk factors for lung cancer and skin cancer, i.e., smoking and sun exposure. This finding is similar to the findings of a study that was conducted by Viswanath et al. (2006), who found that there was a significant association between higher education levels and awareness of the major types of cancer such as lung cancer and skin cancer. Only a few students were aware that behavioral risk factors such as alcohol consumption and the acquisition of the sexually transmitted human papillomavirus could lead to the development of cancer in men and women. Lack of knowledge about these factors is a concern since studies have shown that college students are at risk for engaging in alcohol misuse and risky sexual behavior [31–35].

When asked about what could be done to prevent cancer, many students believed that they did not have control over whether or not they got cancer, indicating that they believe cancer risk is primarily hereditary. The majority of the participants suggested that not smoking and wearing sunscreen could help reduced the chance of developing cancer. Some participants suggested that eating a healthy diet and exercising could also protect against some types of cancer.

*Aspects of Information.* Similar to the findings of previous studies, a large majority of our participants primarily received health information from interpersonal

venues including conversations with family and their healthcare provider [36–39].

Students indicated that they trusted health information from their healthcare provider, and would seek information from their provider if they had a question about their health. The Internet was also a common source of health information, despite the fact that the majority of the students were not using valid measures to assess the trustworthiness of the information. Our findings regarding trusted sources of health information were similar to data from the Health Information National Trends Survey, which suggest that people trust information that is provided by their healthcare provider [40].

The majority of the participants were not able to name common cancer screening tests, including the Pap test or the prostate specific antigen test, despite having been exposed to information about those tests during the CMLT-Listening that administered during the health literacy test session. This suggests that the participants had very low awareness of cancer screening tools that could be used to detect cancer early and did not retain information that was discussed in the CMLT-Listening.

*Aspects of Treatment.* The majority of the participants stated that chemotherapy was the form of cancer treatment that they were familiar with. However, many students viewed chemotherapy as a treatment of last resort, or a form of treatment that was only used when the cancer was aggressive. A few students also mentioned surgery, such as a mastectomy or removal of the tumor, and radiation as forms of cancer treatment.

#### *4.2 Limitations*

The use of a convenience sample of college students from one university is a limitation of this study. In addition, all of the students that participated in an in-depth

interview had an academic major related to public health or a health-care related field. Therefore, the results of this study may not be generalizable to students at other universities or students with other majors.

All of the students that participated in an interview were exposed to the CMLT-Listening, which contains a significant amount of information about cancer, cancer prevention, and cancer screening. Therefore, it is possible that some respondents may have used the information that they learned during the test session to respond to questions during the interview. In addition, social desirability bias is a possible limitation of the study. Although students were informed that their participation in the interview was confidential and instructors would not know the identity of the students that participated, some students may have responded to the investigator's questions in what they perceived as a socially desirable manner.

#### *4.2 Conclusion*

Currently there are no widely accepted measures of cancer literacy. There were significant differences between the participants' CMLT-Listening scores and the qualitative interview data based on Diviani and Schulz's operational definition of cancer literacy. Cancer literacy is an important aspect of functional health literacy. Therefore, there is a need to conduct further research to define and measure cancer literacy in emerging adults.

### *4.3 Practice Implications*

In the US, the lifetime risk of developing cancer for men is 1 in 2 and for women is 1 in 3. Therefore, basic cancer literacy is essential since people with adequate health literacy are more likely to engage in cancer preventive behaviors. Increasing the cancer literacy of emerging adults may lead to an increase in their engagement in preventive behaviors at earlier ages. Cancer education interventions delivered through healthcare providers and the Internet may be effective channels for reaching this population.



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Table 1

*Constructs of the operational definition of the concept of cancer literacy\**

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**Aspects of cancer risks**

Individual behaviors related

Importance of behavioral risk factors

How to reduce cancer risk by changing behaviors

Environmental factors related to cancer

Importance of environmental risk factors

Strength of the relationship between risk factors and cancer development

**Aspects of information**

Trustworthiness of information sources about cancer

Aspects of detection and diagnosis

Existing screenings

Benefits of screenings

Goals of screenings

**Aspects of treatment**

Types of treatments

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\*These are the constructs and sub-constructs that were used. Diviani and Schulz' operational definition of cancer literacy consists of four constructs and 15 sub-constructs.

**Table 2***Qualitative Phase Participant Characteristics, n = 20*

Characteristic	Participants n(%)
Age, M(SD)	22.3
Gender	
Female	14(70.0)
Male	6(30.0)
Race/Ethnicity	
African American	10(50.0)
White	10(50.0)
Year in School	
2nd year undergraduate	6(30.0)
3rd year undergraduate	3(15.0)
4th year undergraduate	4(20.0)
5th year undergraduate	2(10.0)
Graduate or professional	5(25.0)
CMLT-Listening Scores M(SD)(% correct)	21.45(2.1)(86)

## **Chapter 5:**

### **Conclusion**

#### *Overview*

The results of the quantitative phase of this study indicated the majority of the students scored highly on all of the health literacy assessments. However, some students' scores varied depending on the dimension of health literacy that was being measured. The findings of this study were similar to the findings of other studies aimed at assessing individual components of college students' health literacy. In our study and in other studies, students scored the lowest on the eHEALS, which was used to assess their eHealth literacy skills.

Results of the qualitative phase indicated that, overall, students did not have adequate cancer literacy. No existential perceptions, enablers, and nurturers were identified during the analysis of the qualitative data. The results of the qualitative data analysis indicated that the students primarily relied on positive enablers and nurturers, such as healthcare providers and family members, when they sought health information. Furthermore, the Internet was a positive enabler that students used to obtain health information. However, they did not have adequate skills for searching for and evaluating the quality of Internet-based sources. In addition, the teach-back activity revealed that some students have problems recalling spoken health information, especially numerical information.

Three scientific manuscripts resulted from this study and reflect the interrelationships among the results in the two phases. The first manuscript, "A comprehensive assessment of college students' health literacy using a mixed methods approach" presented the results of the quantitative and qualitative phases, and serves to answer the research

question, “Is the level of aural cancer literacy, print literacy, eHealth literacy, or health numeracy associated with the uptake of the HPV vaccine among female and male college students in Alabama?” Students had adequate health literacy according to their scores on the health literacy assessment. Related to this, the second manuscript, “The Association Between Health Literacy and Uptake of the Human Papillomavirus Vaccine Among College Students” presented results from the quantitative phase and provides evidence with regard to the research question, “Is the level of aural cancer literacy, print literacy, eHealth literacy, or health numeracy associated with the uptake of the HPV vaccine among female and male college students in Alabama?” We found that health literacy was not associated with uptake of the HPV vaccine in this population. Finally, the third manuscript, “A mixed methods assessment of the cancer literacy of emerging adult college students” presented results from the quantitative phase and the qualitative phase. Results address the research question, “What factors in college students’ social cultural environment affect the development of cancer literacy?” These findings indicate that college students’ cancer literacy is not adequate according to experts’ opinions about the cancer information that laypeople should know. In addition, the results suggest that quantitative cancer literacy assessments may not accurately identify gaps in knowledge about several aspects of cancer. Taken together, these three manuscripts represent a comprehensive examination of five aspects of health literacy, print literacy, aural literacy, numeracy, eHealth literacy, and cultural and contextual knowledge.

### *Overarching Issues*

Since most students relied on interpersonal communications with the healthcare providers and their family members when seeking health information, it appears that



students may not be frequently using some components of their health literacy skills such as print literacy and numeracy. Given that they were college students, the participants' high scores on the health literacy assessments may have been a reflection of their test-taking skills.

Uptake of the HPV vaccine among emerging adults who were not previously immunized could confer protection for a significant segment of the population, since HPV infections rates are highest in people between the ages of 20 -24. However, the majority of the participants in this study, have very little accurate knowledge of HPV and the HPV vaccine. Therefore, there is a need to increase the number of interventions aimed at this population.

Furthermore, the eHealth literacy skills and health-related numeracy skills of college students need to be addressed. Many colleges and universities required undergraduate students to take at least one personal health course before they matriculate. Health education courses are ideal channels for the delivery of health literacy interventions aimed and improving the health literacy skills of this population. These courses might do well to focus on some of the areas of greatest need for improved health literacy such as the ability to understand prescription bottle instructions or hospital discharge instructions. Understanding how the Affordable Care Act applies to one's personal situation is an area in which health literacy skills may be especially needed.

Additionally, healthcare provider recommendations for the HPV vaccine appear to be the primary mechanism leading to uptake of the HPV vaccine. Therefore, interventions, such as computerized clinical reminders systems, may be effective at

increasing healthcare provider recommendations for the HPV vaccine for people between the ages of 18 and 26.

The findings of this study suggest that many college students have adequate health literacy, but are not using the skills (print literacy and numeracy) that are commonly targeted by campaigns used to promote the HPV vaccine. Some college students may benefit from interventions aimed at improving their eHealth literacy skills and their numeracy. The most effective means of reaching college students is through healthcare providers, health education courses, and their parents. The results of this research also warrant further research into the development of college students' health literacy skills.

A number of limitations within this study were addressed in the three papers. These included: the use of a convenience sample from one university, and the fact that the students in this study had majors related to healthcare or public health, limiting the generalizability of the results; maturation in the form of an increase in cancer knowledge between the quantitative phase and the qualitative phase, the use of extra credit and cash as incentives that could promote socially desirable responses; and the lack of accurate recall regarding uptake of the HPV vaccine leading to misclassification of those who were and those who were not vaccinated. In addition, investigator bias is another potential limitation in the qualitative data collection and interpretation. Potential for such bias may be increased by the fact that a single individual wrote the interview guide and collected and interpreted the data. To minimize this bias the investigator maintained a reflexive journal.

This study was one of the first to look at multiple components of college students' health literacy in relation to decisions about getting the HPV vaccine. The data suggest that, for this sample, health literacy was not related to that particular activity possibly due to students' reliance on family and health care provider advice to make decisions regarding uptake of the vaccine.

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# **Appendix A**

## **eHealth Literacy Scale**

## 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*.

	Not useful at all	Not useful	Unsure	Useful	Very useful
How <b>useful</b> do you feel the Internet is in helping you in making decisions about your health?					

	Not important at all	Not important	Unsure	Important	Very Important
How <b>important</b> is it for you to be able to access health resources on the Internet?					

	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
I know <b>what</b> health resources are available on the Internet					
I know <b>where</b> to find helpful health resources on the Internet					
I know <b>how</b> to find helpful health resources on the Internet					
I know <b>how to use</b> the Internet to answer my questions about health					
I know how to use <b>the health information</b> I find on the Internet to help me					
I have the skills I need to <b>evaluate</b> the health resources I find on the Internet					
I can tell <b>high quality</b> health resources from <b>low quality</b> health resources on the Internet					
I feel <b>confident</b> in using information from the Internet to make health decisions					

## **Appendix B**

### **Short Test of Functional Health Literacy in Adults**

Short Test of Functional Literacy in Adults

**STOFHLA**

READING COMPREHENSION

Hand patient the reading comprehension passages to be completed. Fold back the page opposite the text so that the patient sees only the text.

Preface the reading comprehension exercise with:

“Here are some other medical instructions that you or anybody might see around the hospital. These instructions are in sentences that have some of the words missing. Where a word is missing, a blank line is drawn, and 4 possible words that could go in the blank appear just below it. I want you to figure out which of those 4 words should go in the blank, which word make the sentence make sense. When you think you know which one it is, circle the letter in from of that word, and go on to the next one. When you finish the page, turn the page and keep going until you finish all of the pages.”

Stop at the end of 7 minutes

Passage A: X-Ray preparation

Passage B: Medicaid Rights and Responsibilities

# PASSAGE A

A1	(1)	(0)
a.		
b.		
c.		
d.		

A2	(1)	(0)	A3	(1)	(0)
a.			a.		
b.			b.		
c.			c.		
d.			d.		

A2	(1)	(0)	A5	(1)	(0)
a.			a.		
b.			b.		
c.			c.		
d.			d.		

Sub-Total

PASSAGE A

Your doctor has sent you to have a \_\_\_\_\_ X-ray.

- a. stomach
- b. diabetes
- c. stitches
- d. germs

You must have an \_\_\_\_\_ stomach when you for your \_\_\_\_\_.

- a. asthma
- b. empty
- c. incest
- d. anemia

- a. is
- b. am.
- c. if.
- d. it.

The X-ray will \_\_\_\_\_ from 1 to 3 \_\_\_\_\_ to do.

- a. take
- b. view
- c. talk
- d. look

- a. beds
- b. brains
- c. hours
- d. diets



A6	(1)	(0)	A7	(1)	(0)
a.			a.		
b.			b.		
c.			c.		
d.			d.		

A8	(1)	(0)	A9	(1)	(0)
a.			a.		
b.			b.		
c.			c.		
d.			d.		

A10	(1)	(0)	A11	(1)	(0)
a.			a.		
b.			b.		
c.			c.		
d.			d.		

Sub-Total

## The Day Before the X-Ray

For supper have only a \_\_\_\_\_ snack of fruit, \_\_\_\_\_ and jelly,

- a. little
- b. broth
- c. attack
- d. nausea

- a. toes
- b. throat
- c. toast
- d. thigh

with coffee or tea.

After \_\_\_\_\_, you must not \_\_\_\_\_ or drink

- a. minute,
- b. midnight,
- c. during,
- d. before,

- a. easy
- b. ate
- c. drank
- d. eat

anything at \_\_\_\_\_ until after you have \_\_\_\_\_ the X-ray.

- a. ill
- b. all
- c. each
- d. any

- a. are
- b. has
- c. had
- d. was

A12	(1)	(0)
a.		
b.		
c.		
d.		

A13	(1)	(0)	A14	(1)	(0)
a.			a.		
b.			b.		
c.			c.		
d.			d.		

A15	(1)	(0)	A16	(1)	(0)
a.			a.		
b.			b.		
c.			c.		
d.			d.		

Sub-Total

The Day of the X-ray.

Do not eat \_\_\_\_\_.

- a. appointment
- b. walk-in
- c. breakfast
- d. clinic

Do not \_\_\_\_\_, even \_\_\_\_\_.

- |           |            |
|-----------|------------|
| a. drive, | a. heart.  |
| b. drink, | b. breath. |
| c. dress, | c. water.  |
| d. dose,  | d. cancer. |

If you have any \_\_\_\_\_, call the X-ray \_\_\_\_\_ at 616-4500.

- |               |                |
|---------------|----------------|
| a. answers,   | a. Department. |
| b. exercises, | b. Sprain.     |
| c. tracts,    | c. Pharmacy.   |
| d. questions, | d. Toothache.  |

B17	(1)	(0)
a.		
b.		
c.		
d.		

B18	(1)	(0)	B19	(1)	(0)
a.			a.		
b.			b.		
c.			c.		
d.			d.		

B20	(1)	(0)
a.		
b.		
c.		
d.		

B21	(1)	(0)	B22	(1)	(0)
a.			a.		
b.			b.		
c.			c.		
d.			d.		

B23	(1)	(0)
a.		
b.		
c.		
d.		

Sub-Total

Passage B

I agree to give correct information to \_\_\_\_\_ if I can receive Medicaid.

- a. hair
- b. salt
- c. see
- d. ache

I \_\_\_\_\_ to provide the county information to \_\_\_\_\_ any

- |          |              |
|----------|--------------|
| a. agree | a. hide      |
| b. probe | b. risk      |
| c. send  | c. discharge |
| d. gain  | d. prove     |

statements given in this \_\_\_\_\_ and hereby give permission to

- a. emphysema
- b. application
- c. gallbladder
- d. relationship

the \_\_\_\_\_ to get such proof. I \_\_\_\_\_ that for

- |                 |                |
|-----------------|----------------|
| a. inflammation | a. investigate |
| b. religion     | b. entertain   |
| c. iron         | c. understand  |
| d. county       | d. establish   |

Medicaid I must report any \_\_\_\_\_ in my circumstances.

- a. changes
- b. hormones
- c. antacids
- d. charges

B24	(1)	(0)	B25	(1)	(0)
a.			a.		
b.			b.		
c.			c.		
d.			d.		

B26	(1)	(0)	B27	(1)	(0)
a.			a.		
b.			b.		
c.			c.		
d.			d.		

B28	(1)	(0)	B29	(1)	(0)
a.			a.		
b.			b.		
c.			c.		
d.			d.		

B30	(1)	(0)
a.		
b.		
c.		
d.		

B31	(1)	(0)	B32	(1)	(0)
a.			a.		
b.			b.		
c.			c.		
d.			d.		

Sub-Total

within \_\_\_\_\_ (10) days of becoming \_\_\_\_\_ of the change.

- a. three
- b. one
- c. five
- d. ten

- a. award
- b. aware
- c. away
- d. await

I understand \_\_\_\_\_ if I DO NOT like the \_\_\_\_\_ made on my

- a. thus
- b. this
- c. that
- d. than

- a. martial
- b. occupation
- c. adult
- d. decision

case, I have the \_\_\_\_\_ to a fair hearing. I can \_\_\_\_\_ a

- a. bright
- b. left
- c. wrong
- d. right

- a. request
- b. refuse
- c. fail
- d. mend

hearing by writing or \_\_\_\_\_ the country where I applied.

- a. counting
- b. reading
- c. calling
- d. smelling

If you \_\_\_\_\_ TANF for any family \_\_\_\_\_, you will have to

- a. wash
- b. want
- c. cover
- d. tape

- a. member,
- b. history,
- c. weight,
- d. seatbelt,



B33	(1)	(0)	B34	(1)	(0)
a.			a.		
b.			b.		
c.			c.		
d.			d.		

B35	(1)	(0)	B36	(1)	(0)
a.			a.		
b.			b.		
c.			c.		
d.			d.		

Sub-Total
-----------

\_\_\_\_\_ a different application form. \_\_\_\_\_, we will use

- a. relax
- b. break
- c. inhale
- d. sign

- a. Since,
- b. Whether,
- c. However,
- d. Because,

the \_\_\_\_\_ on this form to determine your \_\_\_\_\_.

- a. lung
- b. date
- c. meal
- d. pelvic

- a. hypoglycemia.
- b. eligibility.
- c. osteoporosis.
- d. schizophrenia.

*Short Test of Functional Health Literacy in Adults (STOFHLA)*

Joanne R. Nurss, PhD., Ruth M. Parker, M.D., Mark V. Williams, M.D., & David W. Baker, M.D., M.P.H.

TOFHLA is a measure of the patient's ability to read and understand health care information, their functional health literacy. TOFHLA Numeracy assesses their understanding of prescription labels, appointments slips, and glucose monitoring. TOFHLA Reading Comprehension assesses their understanding of health care texts such as preparation for a diagnostic procedure and Medicare Rights & Responsibilities.

Date \_\_\_\_/\_\_\_\_/\_\_\_\_

Name \_\_\_\_\_ M \_\_\_\_\_ F

Birthdate \_\_\_\_/\_\_\_\_/\_\_\_\_ Age \_\_\_\_\_ SSN or ID# \_\_\_\_\_

Hospital or Health-care Setting \_\_\_\_\_

City, State \_\_\_\_\_

**Short Form Administered:** \_\_\_\_\_ English \_\_\_\_\_ Spanish

STOFHLA – Score

TOFHLA Total Score:  
Reading Comprehension Raw Score (0-36)

--

Functional Health Literacy Level:

0 - 16 -- Inadequate Functional Health Literacy  
17 - 22 -- Marginal Functional Health Literacy  
23 - 36 -- Adequate Functional Health Literacy


## **Appendix C**

### **Cancer Message Literacy Test-Listening**

## **Cancer Message Literacy Test – Listening**

**\*\*\*Note: This is Shortened Version\*\*\***

### **Sample Video (nightshift work and cancer risk)**

- Scientists do not know why breast cancer occurs more frequently in developed countries.
- 80% of Americans work the nightshift.

### **Cervical Cancer Video**

- There is a new vaccine that can help cure cervical cancer.
- A quarter of women ages 14 to 59 are infected with HPV.
- All types of HPV infections lead to cancer.
- The vaccine protects against some but not all HPV infections.

### **Prostate Cancer Video**

- The PSA test produces an image of the prostate, which will tell the doctor whether you have cancer.
- The doctor recommends proceeding aggressively if the PSA is elevated at all because prostate cancer is so fast growing.
- A high PSA level, which results when the prostate is enlarged or infected, may indicate cancer.
- The doctor will do a digital rectal examination to see whether the prostate is enlarged.

### **Breast Cancer Video (ABC News Report)**

- A woman who learns that she has a genetic mutation that increases the risk of breast cancer knows for certain that she will get breast cancer some day.
- Karen and Denata both tested positive for having breast cancer.
- Taking drugs such as Tamoxifen can reduce the chances of developing breast cancer for women with a genetic defect for the disease.

### **Colon Cancer Video**

- Screening for colon cancer is only necessary if a patient is in the early stages of the disease when it can be treated.
- A family history of cancer should not influence what screening procedure you choose.
- Polyps found in a colon cancer screening may be nothing to worry about or they may indicate possible cancer.

### **Skin Cancer Video**

- The ABCD method was developed by dermatologists to help people

- decide if a mole on their body requires a doctor's attention.
- All skin cancers are found on parts of the body frequently exposed to the sun.
- You are more likely to die from basal cell than malignant melanoma skin cancer.

### **Prostate Cancer - Radio**

- With a new genetic test doctors will be better able to predict whether a given patient is likely to die from prostate cancer.
- Prostate specific antigen test results clearly tell doctors whether a patient needs to be treated for the disease.
- Men who screening results show high PSA levels often get treatments that may not increase their life expectancy.
- Genetic markers for prostate cancer indicate if a prostate cancer will grow quickly or slowly.

### **Mammogram Video**

- It is important not to take any pain relievers right before your mammogram as these may interfere with the results.
- Mammograms lower your risk of getting cancer.
- The best time for a woman to get a mammogram is the week following her period, because her breasts are less sensitive at this time.

### **CT Scans and Cancer Risk Video**

- Experts estimate that CAT scans may cause as many as two out of ten of all cancers today.
- Research shows that for radiation to have an impact on cancer risk your level of exposure would have to equal that of a nuclear plant worker.
- Based on past studies, doctors believe that having just a few CAT scans may significantly raise the risk for cancer.

### **Colon Cancer Radio**

- Early detection only rarely leads to improved outcomes.
- A colonoscopy is the only test currently used to screen for colorectal cancer.

### **Skin Cancer Prevention Video**

- The effects of sun exposure are cumulative, it's the total number of hours that count.
- Sunscreen of at least SPF 15 applied once in the morning can protect you all day in the sun.

**Appendix D**

**The Newest Vial Sign**

## The Newest Vital Sign

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### Nutrition Facts

Serving Size 1/2 cup

Servings per container 4

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Amount per serving

Calories 250

Fat Cal 120

---

%DV

**Total Fat** 13g

20%

Sat Fat 9g

40%

**Cholesterol** 28mg

12%

**Sodium** 55mg

2%

**Total Carbohydrate** 30g

12%

Dietary Fiber 2g

Sugars 23g

**Protein** 4g

8%

---

\*Percent Daily Values (DV) are based on a 2,000 calorie diet. Your daily values may be higher or lower depending on your calorie needs.

**Ingredients:** Cream, Skim Milk, Liquid Sugar, Water, Egg Yolks, Brown Sugar, Milkfat, Peanut Oil, Sugar, Butter, Salt, Carrageenan, Vanilla Extract.



## Questions and Answers Score Sheet for the Newest Vital Sign

		Answer Correct?	
		Yes	No
<p><b>Read to Subject:</b> This information is on the back of a container of a pint of ice cream.</p>			
<p>QUESTIONS</p>			
1.	If you eat the entire container, how many calories will you eat?	_____	_____
<p><b>Answer</b> 1,000 is the only correct answer.</p>			
2.	If you are allowed to eat 60 g of carbohydrates as a snack, how much ice cream could you have?	_____	_____
<p><b>Answer</b> Any of the following is correct:</p> <p style="margin-left: 40px;"> <input type="checkbox"/> 1 cup (or any amount up to 1 cup)  <input type="checkbox"/> Half the container                 </p> <p style="margin-left: 40px;">Notes: If patient answers "2 serving" ask "How much ice cream would that be if you were to measure it into a bowl?"</p>			
3.	Your doctor advises you to reduce the amount of saturated fat in your diet. You usually have 42g of saturated fat each day, which includes 1 serving of ice cream. If you stop eating ice cream, how many grams of saturated fat would you be consuming each day?	_____	_____
<p><b>Answer</b> 33 is the only correct answer</p>			
4.	If you usually eat 2500 calories in a day, what percentage of your daily value of calories will you be eating if you eat one serving?	_____	_____
<p><b>Answer</b> 10% is the only correct answer</p>			
<p>Pretend that you are allergic to the following substances: Penicillin, peanuts, latex gloves, and bee stings.</p>		_____	_____
5.	Is it safe for you to eat this ice cream?	_____	_____
<p><b>Answer</b> <input type="checkbox"/> No</p>			
6.	(Ask only if the patient responds "no" to question 5): Why not?	_____	_____
<p><b>Answer</b> Because it has peanut oil</p>			
<b>Total Correct</b>		_____	

**Appendix E**

**Participant Questionnaire**

# College Student Health Literacy Study

## Participant Questionnaire

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Please enter your Participant Identification Code (PIC) *\*Your PIC was sent in your confirmation email.\** \_\_\_\_\_

### Section 1: Demographic Characteristics

The following questions will ask you about your demographic characteristics.

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

2. What is your gender?

- ☐ Female
- ☐ Male
- ☐ Transgender

3. What is your sexual orientation?

- ☐ Bisexual
- ☐ Gay/Lesbian
- ☐ Heterosexual
- ☐ Unsure

4. What is your race? (Please check all that apply)

- ☐ African American or Black, non Hispanic
- ☐ Asian or Pacific Islander
- ☐ Hispanic or Latino/a
- ☐ Native American, Alaskan Native, or Native Hawaiian
- ☐ White, non Hispanic (includes Middle Eastern)
- ☐ Other Race

**5. What is your relationship status?**

- ☐ Not in a relationship
- ☐ In a relationship but not living together
- ☐ In a relationship and living together

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

- ☐ Single, not married
- ☐ Married/Partnered
- ☐ Divorced
- ☐ Separated
- ☐ Widowed
- ☐ Other

**7. What year are you in school?**

- ☐ 1st year undergraduate
- ☐ 2nd year undergraduate
- ☐ 3rd year undergraduate
- ☐ 4th year undergraduate
- ☐ 5th year or more undergraduate
- ☐ Graduate or professional
- ☐ Not seeking a degree
- ☐ Other

**8. What is your current enrollment status?**

- ☐ Full-time
- ☐ Part-time
- ☐ Other

**9. Are you an international student?**

- ☐ Yes
- ☐ No

**10. What is your major?**

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**11. What is your approximate cumulative grade average?**

- ☐ A
- ☐ B
- ☐ C
- ☐ D/F
- ☐ N/A

## Section 2: Health History

**The following questions will ask you about different aspects of your health.**

**12. How do you describe your current health status?**

- ☐ Excellent
- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor
- ☐ Don't know

**13. What is your primary source of health insurance?**

- ☐ My college/university sponsored health insurance plan
- ☐ My parent's health insurance plan
- ☐ Medicaid or Medicare
- ☐ Another plan health insurance plan
- ☐ I don't have health insurance
- ☐ I am not sure if I have health insurance

**14. Have you ever been diagnosed or treated by a professional for any of the following?**

	Yes	No
Chlamydia	<input type="checkbox"/>	<input type="checkbox"/>
Genital herpes	<input type="checkbox"/>	<input type="checkbox"/>
Genital warts	<input type="checkbox"/>	<input type="checkbox"/>
Gonorrhea	<input type="checkbox"/>	<input type="checkbox"/>
Hepatitis B or C	<input type="checkbox"/>	<input type="checkbox"/>
Human Immunodeficiency Virus (HIV)	<input type="checkbox"/>	<input type="checkbox"/>
Mononucleosis	<input type="checkbox"/>	<input type="checkbox"/>
Pelvic Inflammatory Disease (PID)	<input type="checkbox"/>	<input type="checkbox"/>
Urinary tract infection	<input type="checkbox"/>	<input type="checkbox"/>
Human Papillomavirus (HPV)	<input type="checkbox"/>	<input type="checkbox"/>

**15. Have you ever had sexual intercourse (including sexual, vaginal and anal)?**

- ☐ Yes  
☐ No

**16. Please indicate the gender of your sexual partner or partners that you had within the last 12 months. (please mark the appropriate column for each row)**

	Yes	No
Female	<input type="checkbox"/>	<input type="checkbox"/>
Male	<input type="checkbox"/>	<input type="checkbox"/>

Transgender	<input type="checkbox"/>	<input type="checkbox"/>
-------------	--------------------------	--------------------------

**17. How many people have you had sexual contact (vaginal, oral or anal sex) with?**

- ☐ 0  
☐ 1  
☐ 2  
☐ 3  
☐ 4  
☐ 5  
☐ more than 5

**18. Before today, had you ever heard of a vaccine for HPV?**

- ☐ Yes  
☐ Don't know  
☐ No

**19. Please indicate whether each question is true or false.**

	True	False
People with certain HPV types always develop health problems.	<input type="checkbox"/>	<input type="checkbox"/>
Women can get HPV.	<input type="checkbox"/>	<input type="checkbox"/>
Condoms effectively protect against HPV infection.	<input type="checkbox"/>	<input type="checkbox"/>
HPV can cause cancer of the penis.	<input type="checkbox"/>	<input type="checkbox"/>
HPV may spread from person to person by sexual intercourse.	<input type="checkbox"/>	<input type="checkbox"/>
Males may be infected with HVP and not know it.	<input type="checkbox"/>	<input type="checkbox"/>
HPV infection can be cured with antibiotics.	<input type="checkbox"/>	<input type="checkbox"/>
Men can get HPV.	<input type="checkbox"/>	<input type="checkbox"/>
If you get HPV, you will have HPV for life.	<input type="checkbox"/>	<input type="checkbox"/>
Females may be infected with HPV and not know it.	<input type="checkbox"/>	<input type="checkbox"/>
A person can get HPV by having sex.	<input type="checkbox"/>	<input type="checkbox"/>
HPV infection among women is rare.	<input type="checkbox"/>	<input type="checkbox"/>
Condoms always protect you from HPV.	<input type="checkbox"/>	<input type="checkbox"/>

HPV may be spread from person to person through oral sex.	<input type="checkbox"/>	<input type="checkbox"/>
HPV infection among men is rare.	<input type="checkbox"/>	<input type="checkbox"/>

**20. Please indicate if you agree with the following statements.**

	True	False
Having genital HPV would be upsetting to me.	<input type="checkbox"/>	<input type="checkbox"/>
Having genital HPV would make it difficult for me to get a long-term sexual partner	<input type="checkbox"/>	<input type="checkbox"/>
A vaccine that prevents a sexually transmitted infection is a good idea.	<input type="checkbox"/>	<input type="checkbox"/>
A vaccine that prevents cervical cancer is a good idea.	<input type="checkbox"/>	<input type="checkbox"/>
Getting the HPV vaccine would help me stay healthy.	<input type="checkbox"/>	<input type="checkbox"/>
I am likely to get genital HPV infection in my lifetime.	<input type="checkbox"/>	<input type="checkbox"/>
I am likely to get an HPV-related cancer in my lifetime.	<input type="checkbox"/>	<input type="checkbox"/>
My parents would approve of me getting the HPV vaccine.	<input type="checkbox"/>	<input type="checkbox"/>
My healthcare providers would approve of me getting the HPV vaccine	<input type="checkbox"/>	<input type="checkbox"/>
My religious institution would approve of me getting the HPV vaccine	<input type="checkbox"/>	<input type="checkbox"/>

### Section 3: HPV Vaccine and Cervical Cancer Screening History

**Females Answer Questions 21 and 22**

**Males, Please Skip to Question 23**

**21. Have you ever had a Pap test?**

☐ No (Skip to question 23)

☐ Yes



**22. When is the last time that you had a Pap test?**

- ☐ In the last 12 months
- ☐ 1-2 years ago
- ☐ 2-3 years ago
- ☐ 3-4 years ago
- ☐ 4-5 years ago
- ☐ More than 5 years ago
- ☐ Do not know/do not remember

**23. Have you ever had the HPV vaccine (Gardasil or Cervarix)?**

- ☐ No (Skip to Question 27)
- ☐ Yes

**24. When did you get the HPV vaccine?**

- ☐ In the last 12 months
- ☐ 1-2 years ago
- ☐ 2-3 years ago
- ☐ 3-4 years ago
- ☐ 4-5 years ago
- ☐ More than 5 years ago
- ☐ Do not know/do not remember

**25. How many doses of the HPV vaccine have you received?**

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ More than 3
- ☐ Do not know/do not remember

**26. Please indicate which of the following are reasons that you got the HPV vaccine. (Please check all that apply)**

- ☐ I was worried I might get an HPV-related cancer.
- ☐ I was worried I might get HPV.
- ☐ I was worried I might get genital warts.
- ☐ My healthcare provider recommended it to me.
- ☐ Someone close to me had an HPV-related cancer.
- ☐ Other reason(s)

**Please skip to question 31**

**27. Do you intend to get the HPV vaccine?**

- ☐ No (Skip to question 30)
- ☐ Yes

**28. When do you intend to get the HPV vaccine?**

- ☐ In the next 6 months
- ☐ In the next 12 months
- ☐ In the next 1- 2 years
- ☐ In the next 2 – 3 years
- ☐ Do not know

**29. Please indicate which of the following are reasons why you intend to get the HPV vaccine. (Please check all that apply)**

- ☐ I am worried I might get an HPV-related cancer.
- ☐ I am worried I might get HPV.
- ☐ I am worried I might get genital warts.
- ☐ My healthcare provider recommended it to me.
- ☐ Someone close to me had an HPV-related cancer.
- ☐ My parents made me get it
- ☐ My school required me to get it
- ☐ Other reason(s)
- ☐ Do not know

**Please skip to question 31**

**30. Please indicate which of the following are reasons why do not intend to get the HPV vaccine. (Please check all that apply)**

- ☐ Concerns about vaccine safety
- ☐ Concerns about vaccine side effects
- ☐ Out of pocket cost or insurance copay is too high
- ☐ Long-term consequences of the vaccine
- ☐ I am not likely to get sexually transmitted infections or genital warts
- ☐ Insurance does not cover the vaccine
- ☐ Inconvenience of getting 3 shots
- ☐ I am not currently sexually active
- ☐ I do not like shots
- ☐ I am not likely to develop cervical cancer
- ☐ I am moving/leaving the area
- ☐ Religious beliefs
- ☐ Worried that my parents would find out
- ☐ Worried that my partner would find out
- ☐ Other reason(s)
- ☐ Do not know

## Section 4: Health Information and Health Beliefs

**31. Over the past year, how much information about health and health care did you get from each of the sources below?**

	A Lot	A Little	None
Doctor or other medical personnel	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Family or friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Church or community groups	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Internet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Television	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Radio	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Print material (pamphlet, books, magazines)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**32. Please indicate how much you agree with each of the following statements.**

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
It would be easy for me to talk to my healthcare provider about getting the HPV vaccine.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It would be simple for me to talk to my healthcare provider about getting the HPV vaccine.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It would be comfortable talking to my healthcare provider about getting the HPV vaccine.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**33. Please indicate how much you agree with each of the following statements.**

	Strongly Disagree	Disagree	Neutral	Agree	Strognly Agree
I would receive good information about the HPV vaccine by talking to my healthcare provider.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Talking to my healthcare provider would help me make a good decision about whether or not to get the HPV vaccine.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Talking to my healthcare provider would help me decide I would benefit from the HPV vaccine.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Health Literacy Test Session Schedule

Please select **one** date and time for your health literacy test session.

**The test session will last for one hour.**

June 10th - June 14th

	Monday, June 10th	Wednesday, June 12th	Thursday, June 13th	Friday, June 14th
10:00 am - 11:00 am	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11:30 am - 12:30 pm	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1:00 pm - 2:00 pm	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2:30 pm - 3:30pm	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4:00 pm - 5:00 pm	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

June 17th - June 21st

	Monday, June 17th	Tuesday, June 18th	Wednesday, June 19th	Thursday, June 20th	Friday, June 21st
10:00 am - 11:00 am	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11:30 am - 12:30 pm	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1:00 pm - 2:00 pm	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2:30 pm - 3:30pm	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4:00 pm - 5:00 pm	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Thank you for completing this survey!**

## **Appendix F**

### **Interview Guide**

## Interview Guide

### Introduction

*Thank you for coming to participate in this interview. My goal is to learn how about your health beliefs, your health behaviors, where you like to get health information and your knowledge of cancer and HPV.*

*For the first part of this interview, I will ask you some questions about your health beliefs, sources of health information, and your beliefs about cancer. Then we are going to do an activity called teach back, where I will show you two short videos and I want you to tell me what you learn from each video.*

---

### Section 1: Health Beliefs and Health Behaviors

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*I would like to ask you some questions about your health beliefs and sources of health information.*

- 1) Do you have control over your health?
  - a. If yes, why do you believe that you have control over your health?
  - b. If no, who/what has control over your health
    - i. Why, do you believe that you do not have control over your health?
- 2) What do you do now to prevent health problems when you are older?
  - a. Why do you engage in these activities?
  - b. Where did you learn about these activities?
  - c. What types of health problems do you think you can prevent by engaging in these activities?
- 3) Do you think that there are some racial or ethnic groups that have higher risks for health problems?
  - a. Why do you think that group has a high risk?



- b. What types of health problems are they at risk for?
- c. Where did you learn about this?

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**Section 2: Knowledge and Attitudes about Cancer, HPV and the HPV Vaccine**

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- 4) When I say the word cancer, what comes to mind?
- 5) Are you familiar with any types of cancer?
  - a. What do you know about cancer?
  - b. Where did you learn about this?
- 6) What do you think causes cancer?
- 7) Are you familiar with any types of treatment for cancer?
  - a. Where did you learn about that?
- 8) Do you have control over whether you get cancer?
- 9) Do you think that cancer can be prevented?
- 10) What are some screening tests for cancer?
- 11) Before today, were you aware of HPV?
  - a. Where did you learn about it?
  - b. What do you know about it?
- 12) What are some ways that you can control your risk of getting HPV related cancer?

13) Have you heard about the HPV vaccine?

- a. What do you know about it?
- b. What have you heard your peers saying about the HPV vaccine?

14) Have you ever talked to anyone in your family about the HPV vaccine?

- a. (Yes) What did they say about it?
- b. (No) What health issues do you discuss with your family?
- c. How does your family affect your healthcare decisions?

15) How do you think the HPV vaccine will affect your health?

*[If they have been vaccinated]*

16) Why did you get the HPV vaccine?

17) Was your family involved in the decision to get the vaccine?

18) Where did you get the HPV vaccine? (private doctor, public clinic, school nurse)

19) What are some things that motivated you to get the vaccine?

20) How many doses of the HPV vaccine did you get?

- d. (If person received less than 3) What are some factors that kept you from getting all three shots?
  - i. Probe: parents (i.e. concerns)
  - ii. Probe: cost (i.e. not being able to pay)
  - iii. Probe: side effects

- e. (If person received all 3) What were some factors that influenced you to get all three shots?
  - i. Probe: parents
  - ii. Probe: Reminder from healthcare provider? Other sources?
  - iii. Probe: Insurance
  - iv. Probe: Your school

[If they have not been vaccinated]

21) Do you have any intentions to get the HPV vaccine?

- f. What are some things that would prevent you from getting the HPV vaccine?
- g. What are some things that would motivate you to get the HPV vaccine?
- h. Where would you go if you wanted to get the HPV vaccine?
- i. Where would you go to if you wanted to get information about the HPV vaccine?

---

### **Section 3: Health Information Sources**

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22) The last time that you needed health information, where did you go?

- j. How comfortable do you feel asking your healthcare provider about health information?
- k. Do you ever get health information from the internet?
  - i. What sites do you go to?
  - ii. How do you determine that the information is valid?

- iii. Do you ever get health information from YouTube or social media sites like Facebook?
- l. Do you get information by watching television?
  - i. What types of information appeals to you?
- m. When you see health messages, what are some things that get your attention?
  - i. Does the race or ethnicity of the person delivering the message or on the pamphlet make a difference?
    - 1. Why?
    - 2. Why not?

---

#### **Section 4: Teach Back- Understanding of Messages about HPV and the HPV Vaccine**

---

*Now I am going to show you two videos. I would like for you to tell me in your own words, what each video is about.*

##### **1) Cervical Cancer Video**

[Play the video]

*Can you tell me in your own words what this video is about?*

*Probe: Did anything in the video surprise you?*

##### **2) HPV vaccination for Boys**

*Can you tell me in your own words what this video is about?*

*Probe: Did anything in the video surprise you?*

*That was my last question. Thank you for taking the time to participate in this study. Please feel free to contact me if you have any questions.*

*Thank you!*

## **Appendix G**

### **Results of the PEN-3 Analysis**

### Results of the PEN-3

	Positive	Existential	Negative
<b>Perceptions</b>	<p>Perceived risk of health problems that run in the family</p> <p>Aware of HPV</p> <p>Aware of the HPV vaccine</p> <p>Perceived benefit of getting the HPV vaccine</p>		<p>Not aware of HPV</p> <p>Misconceptions about HPV</p> <p>Not aware of the HPV vaccine</p> <p>No perceived barriers to getting the HPV vaccine</p>
<b>Enablers</b>	<p>Started health behaviors due to information learned in:</p> <ul style="list-style-type: none"> <li>• Nutrition course</li> <li>• Personal health course</li> <li>• African American Health course</li> </ul> <p>Sources of general health information:</p> <ul style="list-style-type: none"> <li>• Nutrition course</li> <li>• African American health course</li> <li>• College/shadowing health professionals</li> <li>• Sociology course</li> <li>• Social media</li> <li>• School</li> <li>• The internet</li> </ul>		<p>Television is not a trustworthy source of health information</p> <p>Lack of health insurance was reason for not completing the HPV vaccine series</p> <p>Social media is not a source of health information</p>
<b>Nurturers</b>	<p>Family is a source of general health information</p> <p>Doctors are a trusted source of health information</p> <p>Doctors are source of information about the HPV vaccine</p> <p>Recommendation from a doctor was the reason for getting the HPV vaccine</p> <p>Information from mother was the reason for getting the HPV vaccine</p>		<p>Do not discuss health issues with family</p> <p>Do not discuss sexual health problems with mother</p> <p>Family not engaging in healthy behaviors</p>

## **Appendix H**

### **Transcripts for the Videos Used During the Teach Back Activity**

## **Transcript for “HPV Vaccine for Boys”**

### **ABC News**

*The video can be located at <http://abcnews.go.com/WNT/video/hpv-vaccine-boys-14806207>*

Now healthy living a health revolution tonight ABC news has learned that tomorrow there may be a new vaccine. And is it time to give this vaccine not every child in this country male as well as female as routine as measles and mumps vaccine. It involves that HPV virus linked to cervical cancer but tonight.

It's not the only disease that could be linked to the virus and here's ABC's chief health and medical editor doctor stated HPV is a common virus, 80% of women have it at some point in their lives. Often it's harmless but for some it can cause cervical cancer. In something you may not expected.

Cancer in men. Phil doesn't smoke he's a picture of health a professional photographer for 21 years, one day while he was shaving he noticed a lump on his neck. When you were diagnose with stage 4 throat cancer what went through your head?

I thought of all things I've missed out on that I didn't do with my children my wife. His case is one of more than 8500 HPV positive head and neck cancers this year. A number that increased dramatically over the last decade.

They think men are getting it from women. Getting the virus through oral sex or other forms of close contact. There is a vaccine against HPV.

But it's controversial. Despite recommendations, less than 50% of girls have gotten it.



Are we missing a really big opportunity here for prevention?

These vaccines are very important. They are just as important as polio rubella mumps and all the other vaccines that young kids receive. Now the CDC is about to urge you to get the vaccine.

I think they'd be crazy not to I think you've got to be vaccinated can now. You know with what the information that's out there. It's just you don't want them waking up and twenty or thirty years and finding out they have stage four throat cancer and that's where I am now.

Such awake up call and you're saying not just cancer but heart disease? Today a new study out today for the first time suggests a link between HPV infection and heart disease in some women. Now if this holds up in any additional studies this could open a door.

,

## **Transcript for HPV Video Used in the CMLT-Listening**

### **Journal of the American Medical Association**

**“Approximately one in four American women have HPV infection – almost half of women ages 20-24”**

<http://archive.is/upiaG#selection-1357.0-1357.93>

A new vaccine on the market prevents human papillomavirus or HPV. which can sometimes lead to cervical cancer. So a new study measured how many American women have HPV. This way, researchers can measure again in a few years to see if the prevalence has gone down due to the vaccine.

In the meantime, researchers discovered that twenty-five million women have HPV Mavis Prawl explains in this JAMA report. Dr. Ira Horowitz see all types of patients who have human papillomavirus or HPV infections.

I'll see teenagers who have had intercourse with just one partner. All the way to women in their 80s. Who've been exposed to the virus and now have manifestations as abnormal Pap smears and precancerous lesions.

He's not surprised by the findings of a new study published in JAMA, the Journal of the American Medical Association. We found that overall, HIV prevalence among females in the United States, ages 14 to 59 years of age as 26.8% and that means 1 in 4 women are infected with HPV.

Dr. Eileen Dunn was part of the study from the Centers for Disease Control and Prevention. She used health data from more than 2,000 women, age 14 to 59 to estimate national HPV infection rates. The prevalence was highest among the 20 to 24 year old women, almost half of those women were infected with HPV. There are hundreds of kinds of HPV infections, some can lead to cancer.

The new vaccine covers two HPV types that cause most cervical cancer and two types that cause genital warts. 3.4% of women had an infection with the types of HPV that could be prevented by the HPV vaccine and that translated to 3.1 million women. But even with the vaccine, cervical cancer screening is important.

**Appendix I**

**Qualitative Data Codebook**

## Codebook

Control Over Health: Lifestyle Choices  
Control Over Health: diet, exercise  
Control Over Health: Weight  
Control Over Health: Visit Doctor  
Control Over Health: Obtain health information  
Control Over Health: smoking  
No Control Over Health: Genetics  
No Control Over Health: Environment/Sedentary Lifestyle  
Prevention: Obesity  
Prevention: Diabetes  
Prevention: Some Cancers  
Prevention: STDs  
Prevention: Heart Disease  
Prevention: Miscarriages  
Prevention Activities: Try to eat right/healthy  
Prevention Activities: Try to exercise  
Prevention Activities: Stress Relief  
Prevention Activities: Exercise  
Prevention Activities: Other (vitamins, drink water)  
Prevention Activities: Vaccines  
Prevention Activities: Prevent STDs  
Prevention Activities: Peers engage in exercise  
Prevention Activities: Start from day one  
Reason for Prevention Activities: To look good  
Reason for Prevention Activities: Prevent weight gain/and association problems  
Influenced Health Behaviors: Mom/Parents  
Influenced Health Behaviors: Active growing up  
No Control Over Health: Cancer  
No Control Over Health: genetics/family history  
Family History of Cancer  
Family History of Other Health Issues  
Want to Prevent Cancer  
Started Health Behaviors: Prevent Freshman 15  
Started Health Behaviors: Entered College  
Started Health Behaviors: Nutrition Class  
Started Health Behaviors: Personal Health  
Started Health Behaviors: African American Health  
No Perceived Risk of Health Issues  
Perceived Risk of Health Issues: High blood pressure  
Do Not Discuss Health Issues With Family

Family Not Engaging In Healthy Behaviors  
Family Healthy Behaviors: Healthy eating  
Family Healthy Behaviors: Not exercising  
African American Health Issues: Diabetes  
African American Health Issues: Stroke  
African American Health Issues: Don't Know  
African American Health Issues: Higher risk for almost everything  
African American Health Issues: other  
African American Health Issues: Sick cell disease  
African American Health Issues: High blood pressure/cardiac stress  
Caucasian Health Issues: Heart Disease  
Causes of Health Disparities: Diet  
Causes of Health Disparities: SES not race  
Causes of Health Disparities: Geographic Location  
Causes of Diabetes: Eating and Physical Activity  
Source of Health Information: Nutrition Class  
Source of Health Information: African American Health Class  
Source of Health Information: College/Shadowing health professionals  
Source of Health Information: Sociology Class  
Source of Health Information: Class  
Source of Health Information: Social Media  
Source of Health Information: Always new about exercise (school, home)  
Source of Health Information: Not pamphlets  
Source of Health Information: Mom  
Source of Health Information: Not Mom  
Source of Health Information: Not Mom for sexual problems  
Source of Health Information: Not Family  
Source of Health Information: Family  
Source of Health Information: Doctor (when visiting)  
Source of Health Information: Doctor (Call)  
Source of Health Information: Not really doctor  
Source of Health Information: Shadowing healthcare professional  
Search for Health Information: Special Times (outbreak, on news)  
Source of Health Information: Internet  
Source of Health Information: Internet (Mayo Clinic)  
Source of Health Information: Internet (NOT WebMD)  
Source of Health Information: Internet (Google)  
Source of Health Information: Internet (WebMD)  
Source of Health Information: Internet (Health Agencies/Organizations)  
Source of Health Information: Peer-reviewed  
Source of Health Information: Wikipedia  
Source of Health Information: NOT Wikipedia  
Source of Health Information: Magazines  
Source of Health Information: Medical based friends  
Source of Health Information: Not Television  
Source of Health Information: NOT print material

Cervical Cancer Risks: Unprotected Sex  
 Cervical Cancer Risks: Not sure  
 Trustworthiness of Internet Sources: More than one source  
 Trustworthiness of Internet Sources: Well known source  
 Trustworthiness of Internet Sources: More than one source  
 Trustworthiness of Internet Sources: More specific symptoms  
 Trustworthiness of Internet Sources: Moderation of the information  
 Trustworthiness of Television Sources: Don't know if they can be trusted  
 Perception of Cancer: Dying  
 Perception of Cancer: Chemotherapy  
 Perception of Cancer: Fear  
 Perception of Cancer: Once you get it you pretty much have it  
 Definition of Cancer: Cells go haywire  
 Definition of Cancer: Misinformation  
 Causes of Cancer: Genetics/family history  
 Causes of Cancer: Not sure  
 Causes of Cancer: The environment  
 Causes of Cancer: The sun  
 Causes of Cancer: Radiation  
 HPV Awareness: Saw information  
 HPV Awareness: Don't know  
 HPV Awareness: High school/college  
 HPV Awareness: Middle school health education class  
 HPV Awareness: Aware but some misinformation  
 HPV Awareness: Not very familiar  
 HPV Awareness: Aware but aware of connection to cancer  
 HPV Awareness: Aware the males and females can get it  
 Control HPV Risk: Vaccine  
 Control HPV Risk: Condom  
 Control HPV Risk: Abstinence  
 HPV Vaccine Awareness: Not familiar/no knowledge HPV Vaccine Awareness:  
 Class  
 HPV Vaccine Awareness: Doctor  
 HPV Vaccine Awareness: Commercial/Media  
 HPV Vaccine Awareness: Slight misinformation  
 HPV Vaccine Awareness: Not peers  
 HPV Vaccine Awareness: Aware  
 HPV Vaccine Awareness: Aware that males can get it  
 HPV Vaccine Awareness: Not aware that males can get it  
 HPV Vaccine Awareness: Learned from mom  
 HPV Vaccine Uptake: Not sure  
 HPV Vaccine Uptake: No  
 HPV Vaccine Intention: Yes  
 HPV Vaccine Intention: Motivated to get it by the video  
 HPV Vaccine Intention: No barriers  
 HPV Vaccine Reason: See the benefit

Doctor Recommendation: Seek more information  
Source of Health Information: Pamphlets (if familiar)  
Social Media: Does not follow health information sources  
Social Media: Not YouTube  
Social Media: YouTube (other information related to health)  
Social Media: Redditt for Health information  
Social Media: Not Facebook  
Social Media: Fraternity uses Twitter to share health information  
Cautious About Vaccines  
Video 1 Teach Back: Not accurate  
Video 1 Teach Back: Accurate/Uncertain About Some Facts (could not remember numbers)  
Video 1 Teach Back: Very vague  
Video 1 Teach Back: Surprise (HPV causes cervical cancer)  
Video 1 Teach Back: Surprise (large number)  
Video 1 Teach Back: Surprise (prevalence among 20 – 24 age group)  
Video 1 Teach Back: Surprise (prevalence among 1 in 4 women have it)  
Video 1 Teach Back: Motivated to seek information  
Video 1 Teach Back: Accurate with precise details  
Video 2 Teach Back: Accurate not precise  
Video 2 Teach Back: Vague  
Video 2 Teach Back: Surprise (Stage 4 Cancer)  
Video 2 Teach Back: Surprise (Men can get HPV)  
Video 2 Teach Back: Accurate with precise details  
HPV in Males: Not aware  
HPV Vaccine for Sons  
HPV And Other Cancers: Aware  
Cancer Prevention: Not smoking  
Cancer Prevention: Some ways to prevent (not specific)  
Cancer Prevention: Depends on the person's body  
Cancer Prevention: Healthy diet  
Cancer Prevention: Exercise  
Cancer Prevention: Stay out of the sun  
Cancer Screening: Skin check  
Cancer Screening: Check for lumps (mammogram not mentioned)  
Cancer Screening: Self Breast Exam  
Cancer Screening: Colonoscopies  
Cancer Screening: Not sure  
Cancer Screening: X-rays  
Cancer Screening: Pap Smear  
Cancer Screening: MRI  
Cancer Screening: CAT Scan  
Cancer Treatment: Chemotherapy  
Cancer Treatment: Surgeries  
Cancer Treatment: Remove it  
Cancer Treatment: Radiation



Cancer Treatment: Drugs  
Cancer Screening Benefits: Early Detection  
Learned about cancer on their own  
Learned about cancer from TV shows  
Attention Grabbing Health Messages: How do you get it  
Attention Grabbing Health Messages: Certain diseases  
Attention Grabbing Health Messages: Alarming images  
Attention Grabbing Health Messages: NOT pamphlets  
Attention Grabbing Health Messages: Freshman orientation packet  
Preferred Health Messages: Race/Ethnicity does not matter