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Understanding Health Literacy and Linguistic Factors Related to African Immigrant Engagement in Primary Health Care in the U.S.

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Understanding Health Literacy and Linguistic Factors Related to African Immigrant Engagement in Primary Health Care in the U.S.

A Major Qualifying Project Report submitted to the faculty of
WORCESTER POLYTECHNIC INSTITUTE
in partial fulfillment of the requirements for the Degree of Bachelor of Science

Submitted by:

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April 27th, 2016

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Abstract

Current methods quantify health literacy using assessments of basic literacy, cognitive skills and economic status. These methods fail to address the role of culture in health care settings. The purpose of this study is to identify and interpret cultural and linguistic differences among African immigrants in Massachusetts and how they translate to use of primary health care services. The results from this study may be helpful in developing interventions to improve African immigrant use of primary care in the U.S.

Acknowledgments

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Introduction

Health literacy is a recently developed area of healthcare research.¹ Similar to the evolution of literacy in the United States, health literacy has transformed from a simplistic, vague concept to a complex, multi-faceted, quantifiable characteristic in healthcare assessment.¹ Throughout the past few decades, the dimensions of health literacy have been debated. One aspect of health literacy that is frequently disputed is the actual definition of the term. The most widely accepted definition of health literacy states it is “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make informed health decisions.”² While the definition of health literacy continues to evolve, the parameters used to quantify it have remained somewhat static.²

Previous research has quantified health literacy through a well-established set of criteria. These criteria include assessment of basic literacy and education³, cognitive skills², socio-economic status³, compliance with healthcare regimens⁴, lifestyle and health behavior⁴, and characteristics such as age and gender.⁴ While these assessments have shown clear connections between health literacy and health outcomes⁵, they do not encompass all contributing factors that determine health literacy. One frequently overlooked aspect of healthcare is the presence and role of culture in the healthcare setting. An individual’s culture may influence his or her perception of healthcare, who he or she may receive care from and when, and how he or she interprets medical diagnoses and treatments⁵. Cultural differences may affect the ability of an individual to understand and interpret health information. Modern assessments of health literacy have made valid connections between health literacy and outcomes, however these assessments often fail to recognize the importance of culture in healthcare and how cultural barriers may affect health literacy.⁵

Background

Current immigrant population in the U.S.

The United States represents one of the most culturally diverse populations in the world. This cultural diversity is partly attributed to the large immigrant population that continues to rise in the U.S. Historically, immigrants have comprised a significant portion of the overall U.S. population, totaling ten percent as far back as 1850.⁶ As of 2013, more than twenty percent of the world immigrant population claimed the U.S. as its destination and over 41.3 million immigrants lived in the U.S.⁶

Massachusetts is home to a large portion of this immigrant population, ranking 9th among states for percentage of population that is foreign born.⁷ One immigrant group in this population that has grown substantially in the past decade is the African immigrant population.⁸ Individuals from vulnerable communities, such as immigrants, have demonstrated a higher incidence of low health literacy when compared to the dominant culture.⁹ This discrepancy has been attributed to differences in reading and writing skills, language, numeracy skills and critical thinking skills which are necessary to navigate the western healthcare system.¹⁰ Previous studies of immigrant populations have shown a

correlation between low health literacy and poor English proficiency, lack of education and economic hardships.¹¹ Additionally, African Immigrants have identified the U.S. healthcare system as being inaccessible and confusing.¹¹

What is health literacy?

Perhaps the most highly debated aspect of health literacy is the definition. The World Health Organization has defined health literacy as the “cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and used information in ways which promote and maintain good health”¹³. Alternatively, the National Institute of Medicine defines the term as “the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make the appropriate health decisions”¹⁴. These are only two sample definitions from highly reputable organizations that demonstrate the variability that persists in the interpretation of health literacy.

Many definitions of health literacy incorporate ideas of cognitive skills, social skills, mental capacity and appropriate decision-making. While a concise and universal definition of health literacy has not yet been developed, for the purpose of this study health literacy will be defined as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make informed health decisions.”² This definition encompasses an assessment based on accessibility and interpretation. Additionally, while this definition is quite similar to the NIM definition of health literacy, it focuses on the ability to make *informed* decisions rather than *appropriate* decisions. This slight change in terminology eliminates the need to define “appropriate” decisions, which would vary vastly among individuals.

Current assessments of health literacy

While the definition of health literacy is still under debate, the criteria for health literacy assessments have solidified in recent years. Studies conducted within recent decades have shown relationships between attributes such as education and income and health literacy⁴. The identified related factors were then used to formulate tools to quantify and assess individual levels of health literacy. Current assessments of health literacy incorporate evaluations of an individual’s basic literacy³, education level³, socio-economic status³, cognitive skills² and history of compliance with health regimens⁴.

Culture and health literacy

While previous endeavors have successfully developed multidisciplinary assessments of health literacy, most continue to neglect culture as a contributing factor. This is particularly important as current assessments may reflect inaccurate or contradicting health literacy measurements when cultural differences are not considered. Culture, like health literacy, has a wide variety of definitions. One particular definition of culture defines it as the “values, symbols, interpretations, and perspectives that distinguish one people from another in modernized societies.¹⁵” This particular definition identifies culture in terms of interpretation and perspective. The way an individual perceives and interprets information or social interactions can greatly impact his or her

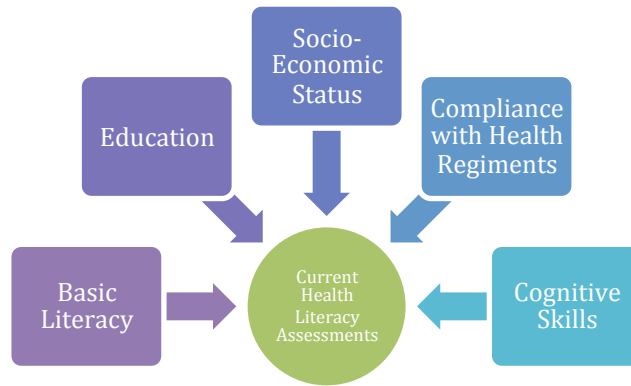


Figure 1 Components of current health literacy assessments

understanding and subsequent decision-making. In a health care setting, cultural differences that generate different interpretations may lead to poor understanding of health information, thus creating the appearance of lower health literacy. Additionally, cultural differences in social or interpersonal interactions can create different perspectives of health information or interactions with the health care system, further contributing to perceived low health literacy.

Incorporating culture into current assessments allows health providers to evaluate health literacy based on interpretation and understanding, rather than understanding alone. Current assessments evaluate understanding of health information via quantitative measures. Quantitative measures include assessments of mathematic capabilities and reading and writing skills, all of which can be quantified by standardized tests. However, when considering culture in the healthcare setting a new category of health literacy assessments are needed. In addition to existing quantitative measures, new qualitative measures can be used to incorporate cultural differences into health literacy assessments. While qualitative measures do not offer concrete numerical evaluations, they offer descriptive and observational data that can offer insight that may be helpful in understanding why quantitative results appear as they do.

Freelist as a cultural assessment

One possible qualitative assessment of health literacy is freelisting. In a freelist exercise, individuals are asked to identify what terms or phrases come to mind when they hear an indicated word. In a health literacy assessment, the freelist assessment would use health terminology to prompt the individual being assessed. The resulting list of terms can be used as an observation of their perception and interpretation of health information. For example, if an individual generates a list of “sick,” “scary,” “death,” and “disease” when given the word “hospital” this may indicate a very negative perception of health care facilities that may affect his or her ability to understand or utilize health information. Additionally, in a large-scale assessment, if individuals from the same cultural background indicate the same perceptions through the freelist exercise this may serve as evidence of cultural differences that could potentially influence health literacy.

Primary Goal and Objectives

Primary Goal

The primary goal of this study is to understand health literacy and the cultural and linguistic differences among African immigrants in Massachusetts as it relates to their use of primary health care services.

Objectives

Three specific objectives have been identified for this study. The first objective is to identify African immigrant interpretation of the United States primary care system and health concepts. The second objective is to assess African immigrant health literacy and engagement in primary health care services. The third and final objective is to integrate results into future interventions in order to improve immigrant use of primary care in the United States.

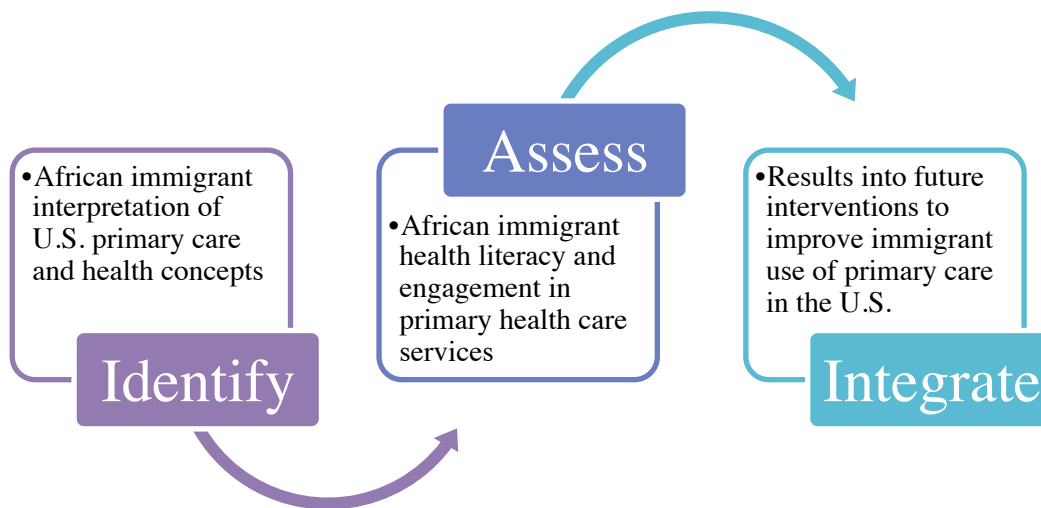


Figure 2: Outline of primary objectives to be completed throughout the duration of the study

Methods

This study began in July 2015 and is currently ongoing. Since the start of the study, a research grant was obtained, the study protocol was reviewed and approved by the University of Massachusetts Medical School Institutional Review Board (IRB), participants were recruited to complete the freelist exercise, health literacy assessment and general health survey, the data were entered into REDCap, and a preliminary analysis was performed on the freelist and general health survey data. The preliminary findings from these analyses were used to assess the demographic of the survey population and to provide a foundation for the formation of focus groups.

Funding Acquisition and Protocol Approval

Before this study began, grant funding for the study was obtained. An application was submitted to the UMass Institute for Applied Life Sciences (IALS) Seed Grant. The grant application was accepted and funding for the study was provided by the 2014 UMass Medical School Graduate School of Nursing (GSN) seed grant.

Once funding was acquired, the study protocol was prepared for IRB review. The IRB serves to protect the rights and well being of human research subjects and must approve all protocols for research involving human participants¹⁶. IRB approval is mandatory for all human research and approval can be obtained from a Food and Drug Administration (FDA) or U.S. Department of Health and Human Services (HHS) registered IRB. Thus, many institutions that regularly conduct human research often have their own IRBs established¹⁶. This study protocol was approved by the UMass Medical School IRB.

IRB approval of this study was contingent upon all members of the research team completing a required training course. The required training course for research staff mandated by the IRB is the Collaborative Institutional Training Initiative (CITI). CITI training provides educational information on rights of human subjects and ensures researchers fully understand the rights and privacy privileges of study participants. All members of the research team completed the CITI training for Biomedical Research Investigators and Key Personnel, Basic Course before beginning work on this study protocol¹⁷.

Participant Recruitment

This study was performed using a Community-Based Participatory Research (CBPR) approach. In CBPR members from the community being studied are actively involved in the research¹⁸. In this approach, throughout the study community members help to recruit study participants and facilitate communication between the research team and the community. These individuals help to develop a relationship between the research team and the community, relay findings from the study that may be of interest to community members and offer insight into the community that may improve understanding of study results and aid in future improvements¹⁸. The community partner in this study was the Africans for Improved Access (AIFA) at the Worcester Multicultural AIDS Coalition (MAC). This group regularly performs community outreach to address chronic health issues such as HIV/AIDS, performs screening and works to improve health care access for African immigrants.

Participants were recruited for this study mainly by community outreach. Two of the research team members were staff members at the Worcester MAC. These two individuals facilitated study recruitment at the MAC facility as well as at other locations within the community. Flyers were made and distributed throughout the community in locations frequented by African immigrants (churches, hair shops, cultural centers). Additionally, study survey stations were held in different venues throughout the community. These recruitment stations were often at religious events, cultural gatherings (such as soccer matches and holiday celebrations) and in local shops frequented by Africans such as hair braiding and specialty stores.

Study Inclusion Criteria

Community members interested in participating in the study must have met the study inclusion criteria set forth in the approved protocol prior to beginning the study. The inclusion criteria for study participation were:

1. Age 18 or older
2. African immigrants currently living in Massachusetts
3. Able to speak and write in English proficiently
4. Able and willing to give informed consent to participate in the study

In addition to the criteria outlined above, participant vision was evaluated using a Rosenbaum Ultimate Eye Chart. Participants with a visual acuity of less than 20/100 were ineligible to participate, as these individuals would have a challenging time completing the survey instruments.

Data Recording and Entry

Data were recorded by two methods throughout the study, either by hand on paper forms or electronically via online survey. Electronic or paper recording was determined based on availability of Internet connection. For both paper and electronic versions, all participants were assigned a three-digit study ID number. The first number in the ID indicated the location where the data were collected and the second two digits indicated the order in which the participant was surveyed from that location. For example, a study ID of 501 indicates the participant was the first participant (01) interviewed at location 5 (a specific church, community center, etc.).

After electronic or paper recording, all data were entered into REDCap, a secure electronic data capture application¹⁹. REDCap allows study data to be entered into personalized forms, tailored to individual studies. Additionally, all data entered into REDCap are highly protected to ensure HIPPA compliance and maintain patient confidentiality. For each new entry into REDCap, a REDCap ID was assigned. Thus, all participants were assigned a study ID (location and participant number) and a REDCap ID.

Health Literacy Instruments

Throughout the study, four separate tools were used to assess health literacy or contributing factors to health literacy. These tools included a general health survey, the Newest Vital Sign assessment, a health literacy assessment tool and a freelist exercise. Participants were asked to complete all four tools to the best of their capabilities. There was no time limit to any instrument used; participants were allowed as much time as needed to complete the survey. Prior to beginning the survey, participants were given a survey factsheet outlining the details of the survey and their rights as participants. A copy of the factsheet used throughout the study can be found in Appendix A. The survey was proctored by a member of the research team and was completed, depending on availability of Internet connection, either electronically or by hand on a paper form.

Freelist Exercise

The freelist exercise was the first tool completed during the survey. A copy of the freelist form used throughout the study can be found in Appendix D. Freelisting is a technique most commonly used in cognitive anthropology to extract information about cultural domains²⁰. Cultural domains are similar to categories, as they represent a set of items that are related or of the same type²¹. An example of a domain could be animals. Within that domain, words such as dog, cat, bear and tiger would be found. In addition, freelisting allows researchers to observe differences in perception and relationships of items within a domain²¹. While simple in design, freelists can be extremely helpful in determining cultural significance based on saliency and frequency of terms²¹.

At the start of the freelist exercise, the survey proctor explained the exercise to the participants and instructed them to fill out either the paper form or the online form. The survey proctor then prompted the participant to write down five to ten words that come to mind when hearing the word “healthy.” This process was repeated with the words primary care, prevention, risk, symptoms, clinic, proactive, screening, check-up, and health insurance. The time at the start and end of the freelist exercise was noted.

Newest Vital Sign

The second tool utilized in the study was the Newest Vital Sign. The Newest Vital Sign (NVS) is a health literacy assessment typically used to rapidly determine patient health literacy in a health care setting. For example, physicians may ask patients to complete the NVS before beginning an appointment. The patient’s ability to correctly answer the NVS questions may help providers to adjust practices to accommodate low literacy patients²².

The NVS uses six questions regarding a given nutrition label to assess a patient’s prose literacy (ability to read basic written items such as ingredient lists or doctor’s orders), numeracy skills (ability to perform basic mathematic calculations such as addition/subtraction and multiplication/division) and document literacy (ability to understand and interpret written technical information such as nutrition facts on a food label)²². The number of questions answered correctly can be used to estimate patient health literacy. Scores of 4 to 6 indicate adequate literacy, 2 to 3 indicate possible limited literacy and 0 to 1 indicate likely limited literacy²². A copy of the NVS sheet (with correct answers indicated) used throughout the study can be found in Appendix C.

During the NVS portion of the survey, participants were instructed by the proctor to write their answers on the written sheet or input them into the electronic form. Participants were allowed a calculator and writing utensil to complete this form.

Additional Health Literacy Assessment Tool

In addition to the NVS, a second health literacy assessment tool was used. Unlike the NVS, this tool is not a standard assessment tool. Rather, the tool was created for the purpose of this study. This health literacy assessment tool focused primarily on health literacy in the context of health promotion information. The tool was a multimedia assessment, assessing participants’ ability to interpret health promotion information from written materials, audio recordings and videos. The following components were included in the assessment:

1. Ability to interpret information on a food label regarding cholesterol

2. Ability to use a hospital map to locate a structure
3. Ability to follow an automated phone recording and select the appropriate option
4. Ability to interpret information on a stroke prevention flyer
5. Ability to identify muscle groups used in an exercise video
6. Ability to interpret information from data produced in a health study

For this section of the survey, the proctor instructed the participant to follow the directions on the tool and provided assistance with technical aspects (starting audio recording, starting the video, using the calculator) when necessary.

General Health Survey

The final tool utilized in the study protocol was a general health survey. A copy of the survey used throughout the study can be found in Appendix B. The general health survey was utilized to gather demographic data for the participant group. The survey was designed to elicit information regarding participant's immigration status, native country and languages, educational background, financial situation, health status and previous engagements in the U.S. health care system. The study proctor instructed the participants to fill out the form and offered clarification when needed.

Participant Observation and Acceptability of Instruments

Two additional tools were utilized throughout the study to provide supplemental insight into participant perception of study instruments. These supplementary assessments were the observation tool and the acceptability of health literacy tool/NVS. The purpose of these assessments was to evaluate participant experience throughout the survey and identify possible pitfalls in the survey.

Observation Tool

The survey proctor completed the observation tool. Throughout the survey, the proctor observed the body language and behavior of the participants. At the completion of the survey, the proctor noted the participant's body language, any comments made or important questions the participant asked and any other observations about the participant's behavior.

Acceptability of Health Literacy Tool and Newest Vital Sign

After completing the health literacy tool and NVS tool participants were asked to complete two separate post-surveys. The post-surveys were identical for both tools. The surveys asked participants to rank several statements on a scale of agree to disagree. Some sample statements are:

1. I found these questions difficult to answer.
2. These questions made me feel uncomfortable.
3. I knew most of the answers to these questions.

Responses to these post-surveys may be used to alter survey questions for future endeavors or to assess trends found in the NVS and health literacy tool data.

Data Analysis

Demographic Data

The data presented in this document only reflect preliminary analysis of an incomplete data set. Once the study reaches completion, the demographic data and sample characteristics will be analyzed using the statistics software SPSS. The preliminary data presented for sample characteristics were generated using manual entry into Microsoft Excel. No statistical analysis was performed on these data due to the small sample size.

Health Literacy Assessment Data

The health literacy assessment data will be analyzed via regression analysis to determine relationships between factors associated with health literacy and predicted literacy. First health literacy assessment responses will be scored to produce two health literacy scores for each participant (one score for the NVS and one score for the health promotion assessment). Health literacy scores will then be paired with education level, salary, years in the U.S., and other demographic data. Regression analysis will be performed to determine the strength of any relationships found between health literacy assessment scores and demographic information. These analyses will be performed after study completion (n=100).

Freelist Data

The freelist data were analyzed with Visual Anthropac. Visual Anthropac is an anthropologic software system used to analyze qualitative and quantitative data in the form of freelists and pilesorts to yield information regarding cultural domains²³. The raw freelist data was first cleaned to eliminate spelling errors and formatting issues. Members of the research team then recoded the raw freelist responses into related categories. For example, if the words food, eating, diet and calories all appear as freelist responses, these words can be recoded into the category 'nutrition'. However, terms that did not fall into any redefined category were left as is. The raw freelist responses were entered into Visual Anthropac along with the corresponding recoded list and respondent demographic data. Visual Anthropac utilizes respondent-by-item matrices to analyze frequency and saliency of terms in a freelist. The top 20-30 most frequent or salient terms are assumed to be shared among a cultural group. A second matrix, a respondent-by-respondent matrix is then used to show diversity among responses. This secondary analysis can be filtered in Visual Anthropac to show relationships based on gender, race, language or other factors associated with the freelist. The preliminary freelist analysis presented in this report shows results for the terms "healthy" and "prevention". The responses are categorized based on participants' region of origin.

Results

The following results reflect a preliminary analysis of the study data collected thus far. The data reflect approximately 50% of the study population (n=48 for all data shown, final results will reflect n=100). No statistical analyses were performed on this data subset due to small sample size. The complete data set will be analyzed for statistical significance after study completion.

General Health Survey- Preliminary Findings

Sample Characteristics

The general health survey tool collected data regarding participant demographic and characteristics. The main characteristics assessed in the general health survey were participant age, gender, country or region of origin, length of residence in the U.S., salary, and highest level of education completed.

Age and Gender

The study requirements indicate that all participants must be 18 years of age or older to participate. Thus, the youngest participants in the study were 18 years old. Preliminary analysis of the first 48 participants, displayed in figure 3, indicates that this data set has a range of 46 years, with the oldest participants being 64 years old. Over 50% of study participants were between the ages of 25 and 44.

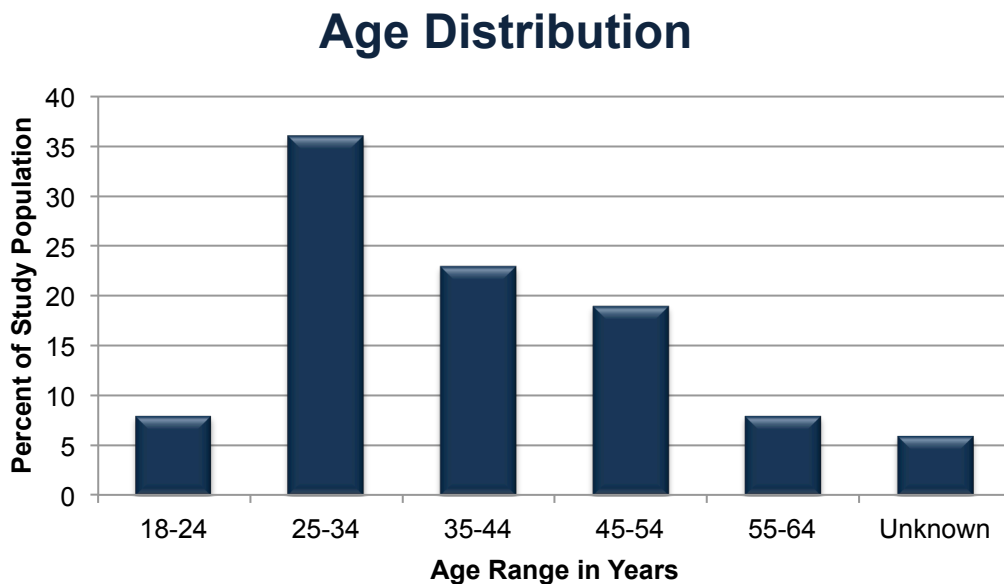


Figure 3: Age distribution of study participants

Figure 4 displays the results of primary analysis on gender of the first 48 participants in the study. These results show that 53% of the study population is female

and 47% of the population is male. These preliminary results indicate that there is approximately an equal distribution of male and female participants thus far.

Gender

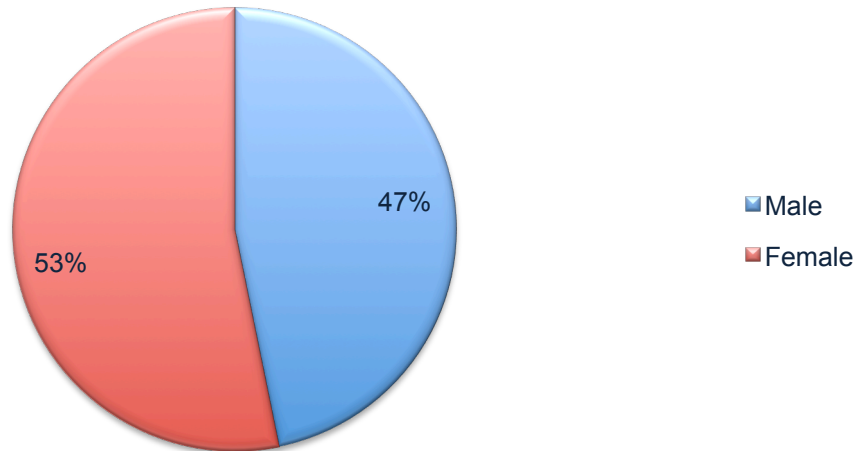


Figure 4: Gender distribution of study participants

Country of Origin

In the general health survey, participants were asked to identify their country of origin. Initial analysis revealed that over 50% of participants surveyed originated from countries in West Africa (data not shown). Additionally, within the group of participants originating from West Africa, over 40% identify Liberia as their country of origin. The remaining participants originated equally from eastern and central African counties.

West African Country of Origin	
Benin	4%
Cape Verde	11%
Ghana	11%
Liberia	41%
Mali	4%
Nigeria	19%
Senegal	4%
Sierra Leone	7%

Figure 5: Percentage of participants originating from West African countries

Length of Time in the U.S.

Participants were asked to indicate how many years they have resided in the United States. Additionally, participants were asked to identify their immigration status (permanent resident, green card, illegal, etc.) These data are not shown in this document, but will be processed in the final analysis of the complete data set. Preliminary analyses of the first 48 participants in Figure 6 indicate that nearly 70% of participants have lived in the U.S. for more than 10 years.

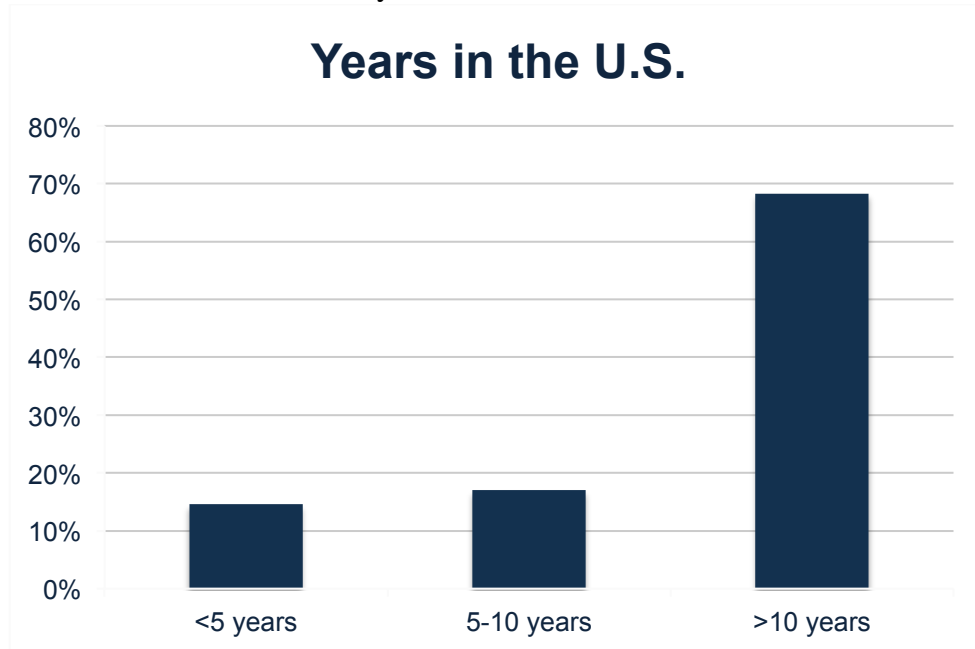


Figure 6: Years of residence in the United States

Salary Range

One of the final segments of the general health survey asked participants to provide information regarding their employment, household and income. Employment and household (number of individuals per household) were not analyzed in this preliminary analysis. Income data (total household income per year) for the first 48 participants was analyzed and is displayed in Figure 7. These data indicate the participant group had an income range of under \$5,000 to \$199,000 per year. A majority of participants (over 60%) indicated income between \$29,000 and \$99,000 per year. However, 11% of participants indicated severely low income of less than \$5,000 per year. These data do not reflect number of people per household or personal salary information. Further analysis will be performed at study completion to incorporate these contributing factors.

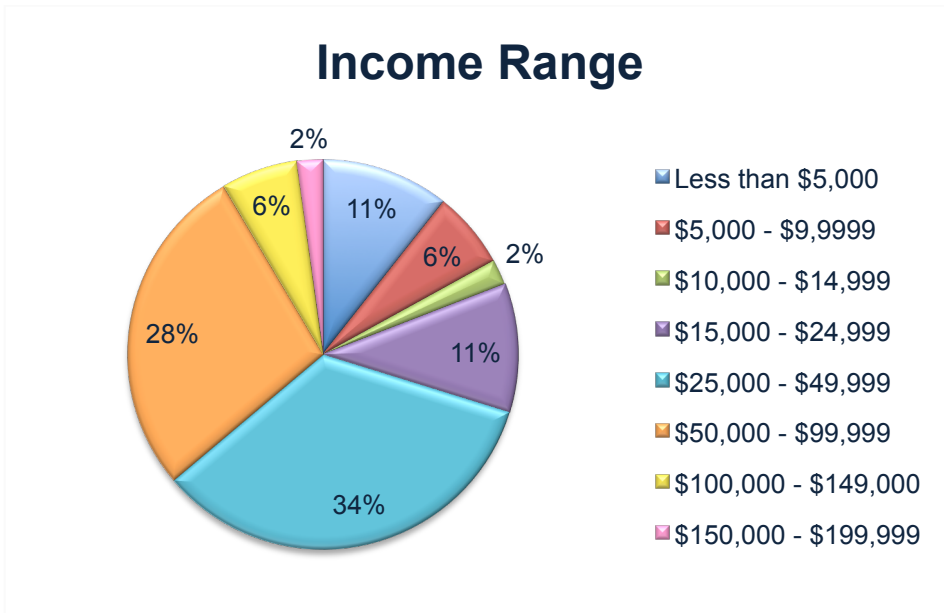


Figure 7: Average estimated income ranges of study participants

Education Level

Participants were asked to indicate the highest level of education that they have fully completed. This assessment did not discern whether or not the education indicated was completed in the United States, in the participant’s native country, or elsewhere. Preliminary analysis shown in Figure 8 demonstrates that nearly 90% of participants surveyed thus far have completed some college or higher degrees of education. Additionally, nearly 30% of participants indicate completion of a graduate degree.

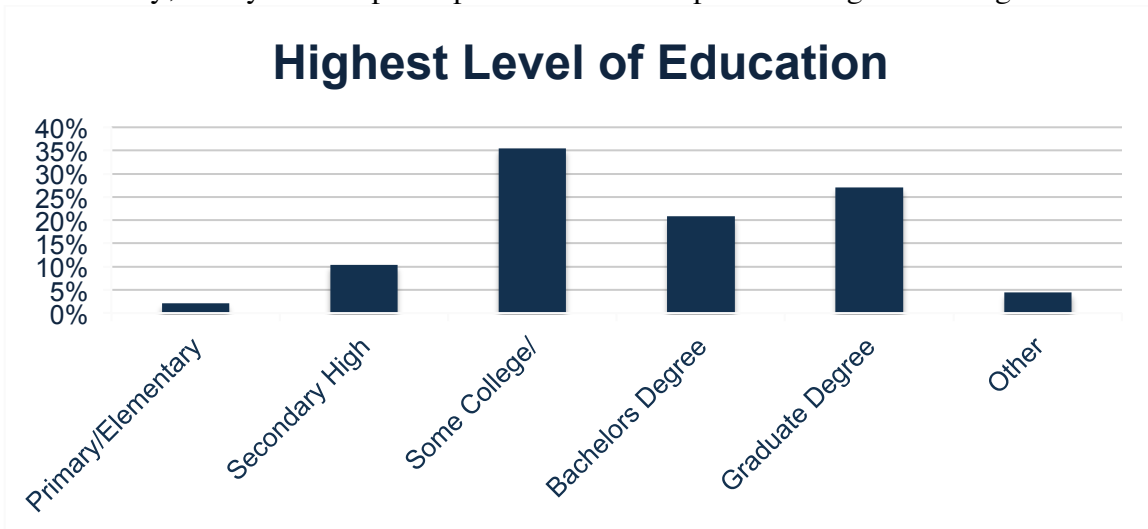


Figure 8: Highest level of education completed by study participants

Health Care Engagement- Preliminary Findings

In addition to demographic information, the general health survey was used to gather insight into study participants' current engagements in the U.S. health care system. These assessments elicited information regarding participant primary care providers, health insurance, number of office visits, diagnosis of chronic disease, interactions with care providers and perceived health condition.

Use of Primary Care and Health Insurance

Data collected from the general health survey shown in Figure 9 indicate that nearly all study participants are currently engaged in the U.S. primary care system. Over 80% of participants indicate that they have a physician that they see on a regular basis and consider their primary care physician (PCP). Additionally, 94% of participants surveyed indicate that they currently have health insurance. Insurance type (private, Medicaid, Medicare, etc.) was also identified in the survey. These data were not analyzed in the preliminary analysis, but will be taken into consideration in later analyses.

	Yes	No
Have PCP	81%	19%
Have Health Insurance	94%	6%

Figure 9: Current participant engagements in U.S. health care system

Engagement with Health Care Providers and Perceived Health

Several questions on the general health survey elicited information regarding participants' ability to interact with health care providers (HCPs). These questions asked participants to rank their perceived difficulty conveying information to HCPs in addition to their perceived difficulty in understanding information given by HCPs. Preliminary results show that 90% of participants find it easy or very easy to describe their condition to HCPs. These data are shown in Figure 10 below.

How easy is it for you to describe how you feel to a doctor?

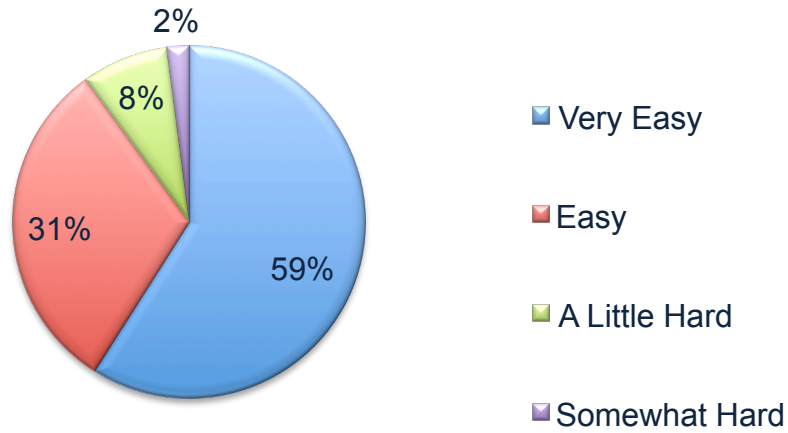


Figure 10: Self-assessment of ability to interact with health care providers

Additionally, participants were asked to describe their current state of health. This was a simple self-assessment where participants indicated which category they felt they belonged to. These data were not based on any health examination or health records. Preliminary results shown in Figure 11 display that over 75% of participants believed themselves to be in excellent or very good health.

Self-rating of Overall Health

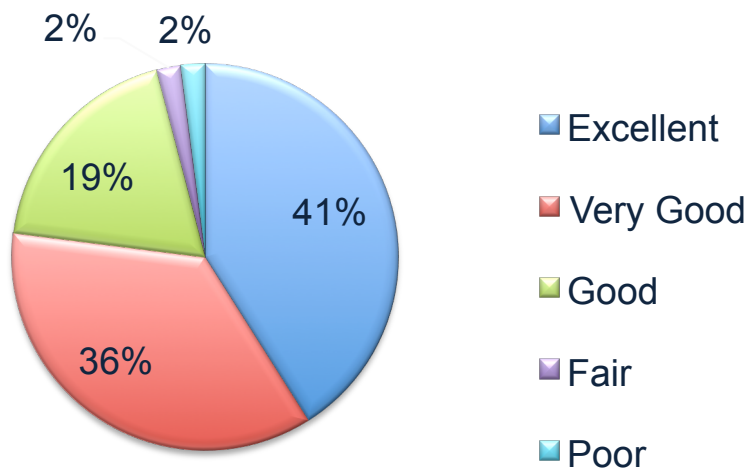


Figure 11: Self-assessment of current health status

Freelist results for “Healthy” and “Prevention”

The raw freelist responses to terms “healthy” and “prevention” were analyzed in this preliminary analysis. The research team recoded the raw lists and the data were entered into Visual Anthropac. For this analysis, the Anthropac analysis was configured to yield response frequencies by region of origin. The regions identified in this analysis were Central Africa, Eastern Africa and Western Africa. The frequencies of terms in these three domains were compared to the overall frequency of the terms.

Figure 12 shows the preliminary results for freelist responses to “healthy”. The most frequent responses to “healthy” are shown on the horizontal axis. These responses include diet, fitness, absence of symptoms and wellness. The recoding process in the freelist analysis assigned different terms to these response categories. The “diet” response category contains terms such as nutrition, food, eating well, etc. The “fitness” response category was assigned to responses such as exercise, workout, gym, etc. Responses such as feeling good, not sick, negative test results, etc., were assigned to the absence of symptoms category. Lastly, the wellness category contains responses similar to sleeping, taking care of myself, stay active, etc.

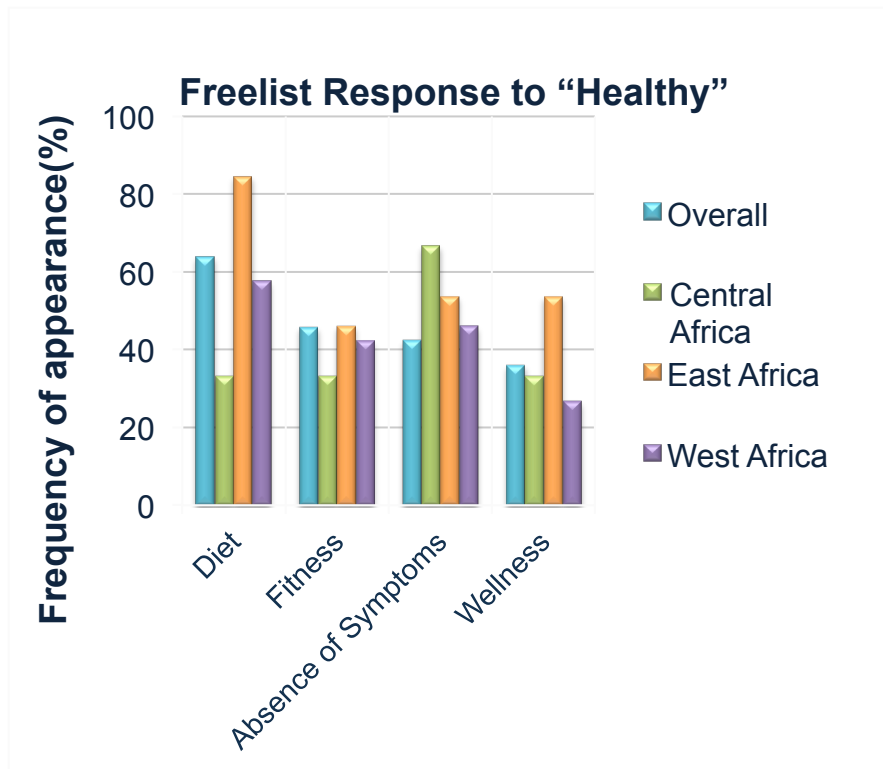


Figure 12: Freelist results for ‘healthy’ responses by region

The data above show similar frequencies among all three cultural domains. In particular, the frequencies of fitness and wellness related to “healthy” appear consistent. This indicates that these terms are present in all three cultural domains. There appears to be a significant difference among the domains in the response “diet”. East African populations show a high frequency (over 80%) of the word “diet” as a response to healthy, whereas the Central African population demonstrates a much lower frequency

(approximately 30%). This may indicate that differences exist among cultural domains in reference to this understanding of health. A high frequency of response coded as “diet” may indicate a cultural consensus. In contrast, a lower frequency (below 50%) of this term may serve to indicate the absence of a relationship between diet and health in that cultural domain. Another possibly significant result is shown under the response “absence of symptoms” Central and East African populations indicate a 50% or higher frequency of the response “absence of symptoms” to the given word “healthy”. These frequencies may be significant in identifying lack of symptoms as a cultural identifier for healthy within these domains.

The preliminary freelist responses to “prevention” are shown below in Figure 13. In this analysis, the category “healthy behavior” contained terms that implied positive actions that contribute to health. Responses included use of protection in sexual encounters, encouraging others to make positive choices, and being responsible for one’s health. The category “prevention” included responses that were variations or direct repetitions of the given term prevention. The category “health practice” contained responses that directly referred to actions in a health care environment. These response included disease testing, going for checkups, etc. The final category “diet” was assigned to the same range of responses seen in the analysis of “healthy responses.

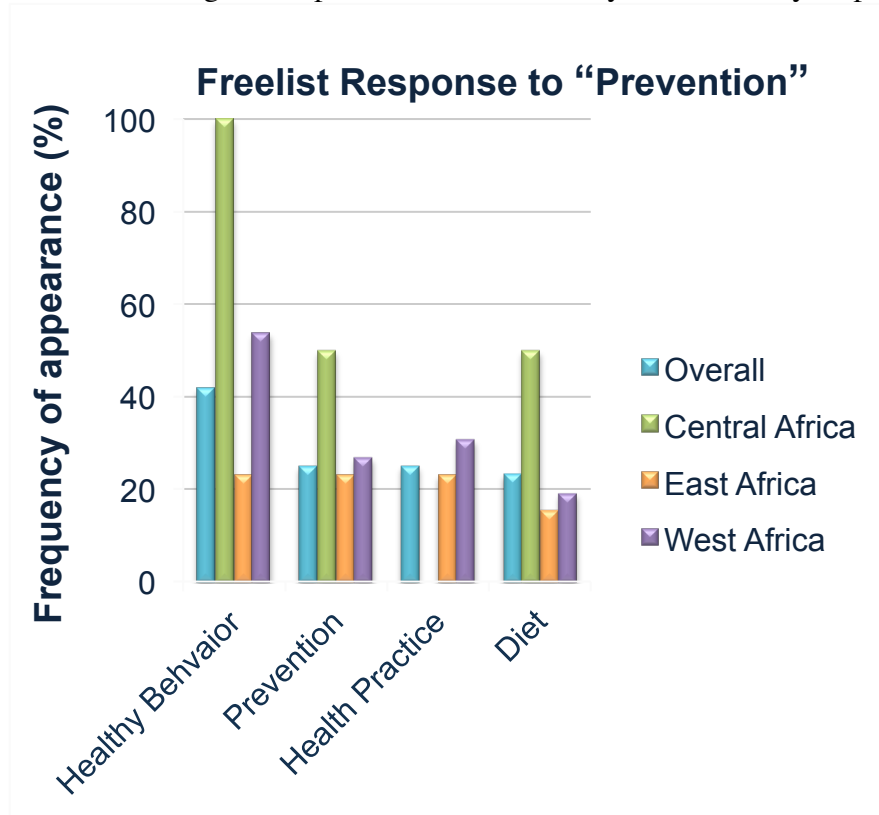


Figure 13: Freelist results for ‘prevention’ responses by region

Preliminary analysis of “prevention” responses demonstrates lower incidence of consensus among cultural group responses in comparison to the “healthy” responses. The most seemingly significant frequencies are seen in the healthy behavior category. 100% of Central African participants indicated that healthy behavior is a main component of

prevention. About 50% of the Western African population indicated the same consensus. The Central African population also indicated a high frequency of prevention and diet responses. However, all other responses had frequencies under 50% for all regions and in the overall study population. Thus, there are no strong indications of cultural differences in this data set.

Discussion

Health literacy is a component of the U.S. health care system that has increased dramatically in importance in the past decade. Health care providers have begun using standardized health literacy assessments to gauge patient health literacy. These assessments are then used to modify treatment plans, care instructions and dissemination of health information in order to effectively communicate with patients and ultimately to produce better health outcomes and care compliance.

While health literacy is an important factor contributing to health outcomes of native U.S. citizens, it is perhaps far more important when considering health outcomes of immigrant populations. The United States has been a major immigrant destination for decades. In recent decades, immigration to the U.S. has increased dramatically. Currently, over 20% of the world immigrants reside in the United States⁶. More specifically, a substantial portion of this immigrant population lives in Massachusetts. Research has indicated an increased risk for low health literacy and poor health outcomes in vulnerable populations, such as immigrants⁹. While current health literacy assessments may be used to address this discrepancy, they lack a cultural context, which may be vital when considering immigrant engagement in the U.S. health care system.

This study was designed to identify possible cultural domains in African immigrant populations in Massachusetts that may impact health literacy and ultimately health outcomes. The end goal of the study is to have 100 participants complete the study. The study involves a three-part survey consisting of a general health survey, a health literacy assessment and a freelist exercise. The primary objectives of the study are to assess African immigrant health literacy, identify possible cultural domains and integrate this information to yield better health literacy assessments. This study has not yet reached completion and is ongoing. The data presented in this report represent a preliminary analysis of the first 48 participant responses and have not been evaluated for statistical significance. A secondary, complete analysis will be performed after all participant data have been collected.

Sample Characteristics- Preliminary Analysis

The demographic data collected throughout this study were analyzed to yield information regarding sample characteristics. The sample characteristics were first used in conjunction with freelist and health literacy data to identify possible relationships between demographic components and basic health literacy scores. Second, the demographic data were used to determine any bias or skew in the sample. Lastly, the demographic data were used to identify possible cultural domains in conjunction with the freelist response results.

Preliminary analyses of the sample characteristics demonstrate that the sample has a wide age range and a rather even distribution of male and female participants. The data appear to show a higher incidence of younger participants. A majority of study participants fell within the 25-35 age range, while less than 30% of participants were older than 44 years old. However, it is not clear as to whether or not this is significant. It is possible that this age distribution is a result of the survey locations. The cultural events used as survey collection sites (such as soccer tournaments) showed a tendency to attract a younger population. The equal distribution of male and female participants indicates that at this point there is no gender bias in the study.

In contrast, these data do demonstrate a potential regional bias in the study population. A majority of study participants originated from Western African countries. Of these participants, more than 40% were Liberian. This bias is attributed to the community outreach process used in the study protocol. Liberian immigrants operate the Worcester Multicultural AIDS coalition, a major data collection site. Thus, cultural similarities and mutual trust have increased Liberian participation in the study. This bias will be considered in the final analyses of complete study data as it may impact the overall scope of the study, limiting interpretation to certain African populations rather than the entire African immigrant population as a whole.

Engagement in U.S. Primary Care System- Preliminary Analysis

Nearly all of our assessments of immigrant engagement in the U.S. health care system indicate that our study population is currently engaged in the U.S. system. Over 80% of participants indicated that they currently have health insurance and see a primary care physician (PCP) on a regular (at least yearly) basis. Additionally, preliminary analyses indicate that most study participants are comfortable engaging with health care providers. 90% of participants expressed that they are capable of conveying symptoms to a provider and similar results were seen in participant ability to understand information given to them from a provider and participant ability to communicate lack of understanding to providers (data not shown). Based on these preliminary analyses, it appears that any incidence of low health literacy would not be attributed to lack of engagement in the U.S. health care system.

Freelist- Preliminary Analysis

Analyses of the freelist responses to “healthy” and “prevention” show possible emergence of cultural domains. In the “healthy” responses the data show a strong association between the term “healthy” and diet and lack of symptoms. The possible association between healthy and diet is a positive (beneficial) result. If this relationship exists in all cultural domains, this would indicate that there are no culturally significant differences present. Thus, the idea that maintaining one’s health is related to one’s diet or nutrition is translated well across cultural groups. However, the association between healthy and lack of symptoms may indicate a negative (detrimental) result. The high frequency of “lack of symptoms” responses to the term “healthy” indicates a possible difference among cultural domains. Cultural groups that associate lack of symptoms with health indicate an interpretation where an individual who does not feel sick, or does not have visible symptoms, is healthy (not sick). The differences in cultural interpretations of health have the potential to influence engagement in primary care and ultimately health

outcomes. Individuals from cultural groups that recognize health as not feeling sick, may only engage in the health care system when they are symptomatic, rather than routinely receiving primary maintenance care. This limited engagement in health care could prevent early detection and treatment of disease, putting individuals at a higher risk for severe illness and poor health outcomes.

The freelist responses to the term “prevention” do not appear to indicate any strong cultural differences or similarities. The response “healthy behavior” had a frequency of 100% in the Central African population, indicating a strong association. However, the Central African population was much smaller than the other cultural groups in the study, therefore this consensus may change when more responses are included in the final analysis. The remaining response frequencies for all cultural groups in the “prevention” analysis demonstrate a frequency of 50% or less. Thus, more data is needed to determine the presence or absence of cultural differences in the interpretation of “prevention”.

Future Developments

This study is ongoing and is expected to be complete by June 2016. At the time of study completion, all data will be analyzed in full and assessed for statistical significance. In addition to the analyses performed in this preliminary assessment, additional factors will be considered. After data collection is complete, participant health literacy will be assessed based on the current health literacy assessment tools (NVS and health promotion results). The predicted health literacy scores will then be compared to freelist data and cultural domains. The comparison of health literacy scores and freelist responses will be used to suggest whether or not cultural domains appear to affect health literacy in the study population. After final data analysis is complete, focus groups will be conducted. Data from the freelist responses will be used to formulate questions and group pile sorting exercises to be used in the focus groups.

While this study only represents a small subset of African immigrants in Massachusetts, the results have the potential to impact a larger population. The small sample size and potential demographic skews in the study data pose potential limitations on the ability to make generalized conclusions. However, findings from this study may be used to assess the impact of culture on health literacy of other immigrant populations within the state or throughout the country. Additionally, significant findings from this study may be used to alter communication techniques in the U.S. health care system in order to improve immigrant use of primary care and ultimately produce better health outcomes.

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Appendix A: Survey Factsheet

H00005931
2.28.15

UNIVERSITY OF MASSACHUSETTS MEDICAL SCHOOL COMMITTEE FOR THE PROTECTION OF HUMAN SUBJECTS IN RESEARCH

FACT SHEET

- A. You are invited to take part in a research study called “Finding Words That Work: Considering Culture and Health Literacy.”
- B. The purpose of this study is to learn what African immigrants think about when they hear words related to health and health care in the U.S. We also want to learn if anything makes it hard for you to find, understand, and use information about health and health care.
- C. You will be in the study for about 30 minutes. You do not need to go anywhere. The research will be done right here.
- D. As part of this study, you will be asked to do 4 things.
 - 1) **Read some letters** off a paper to check if you can see well enough to read our surveys.
 - 2) **Write a list of words** you think of when you hear words about health and health care.
 - 3) **Fill out a survey.**
 - 4) **Complete two forms on health literacy.**

You will get a \$20 gift card if you do **all** 4 things.

- E. One of the risks of being in this study is that your personal information could be lost or seen by others. This is not likely to happen. You may feel some stress if you don't know how to answer some of the questions. **Your name will not be on any of the forms** you fill out and we will do all we can to make sure that your information is protected.
- F. Taking part in the study is **voluntary**. You do not have to be in this study, and if you do join, you can stop or leave at any time. There are no penalties if you want to stop.
- G. If you have any questions, concerns, or complaints, or think that the research has hurt you, you can talk to Chioma Nnaji at (617) 595-6888 or Nancy Morris at (508) 856-3661. This research has been reviewed and approved by an Institutional Review Board. You can reach them at (508) 856-4261 or irb@umassmed.edu if you would prefer to speak with someone who is not a part of the study or have questions about your rights as a research subject.

Appendix B: General Health Survey

African Immigrant Health Survey (H00003591)

ID #: _____

Please answer every question.

Location: _____

Coming to the U.S.

1. In what country were you born? _____
2. Did you live in any other country besides the one you were born in **before moving** to the United States?
 No
 Yes,
If yes, please list the last 3 countries you lived in and how long you lived there.
Name of country: _____ Years: _____
Name of country: _____ Years: _____
Name of country: _____ Years: _____
3. In what **year** did you first move to the United States? _____
4. How **old were you** when you moved to the United States? _____
5. What is your current immigration status?
 I am a permanent resident with a green card
 I have an active visa
 I am undocumented
 I am a refugee
 I am an asylee
 I have temporary protected status
 I am a U.S. citizen
6. How many times have you **visited** your country of origin during the last 12 months? _____
7. Do you **send money** to relatives in your country of origin? **(Choose only one response)**
 No
 Yes, I usually send \$ _____ monthly
 Yes, I usually send \$ _____ a few times a year
 Yes, I usually send \$ _____ once a year

Please answer every question

ID #: _____

Language

8. What language do you speak most often? _____

9. What is the **primary language** spoken in your home here in the United States?

- | | | | |
|----------------------------------|---------------------------------|---|---------------------------------------|
| <input type="checkbox"/> English | <input type="checkbox"/> Creole | <input type="checkbox"/> Luganda | <input type="checkbox"/> Swahili |
| <input type="checkbox"/> Akan | <input type="checkbox"/> Ewe | <input type="checkbox"/> Mandingo | <input type="checkbox"/> Yoruba |
| <input type="checkbox"/> Arabic | <input type="checkbox"/> French | <input type="checkbox"/> Pidgin English | <input type="checkbox"/> Twi |
| <input type="checkbox"/> Amharic | <input type="checkbox"/> Ga | <input type="checkbox"/> Portuguese | <input type="checkbox"/> Yoruba |
| <input type="checkbox"/> Bemba | <input type="checkbox"/> Igbo | <input type="checkbox"/> Somali | <input type="checkbox"/> Other: _____ |

10. How well do you **understand** English when someone is speaking to you?

- Very well
- Somewhat well
- Not very well
- Unsure

11. How well do you **speak** English?

- Very well
- Somewhat well
- Not very well
- Unsure

12. How well do you **read** English?

- Very well
- Somewhat well
- Not very well
- Unsure

13. How well do you **write** in English?

- Very well
- Somewhat well
- Not very well
- Unsure

Please answer every question

ID #: _____

Health care experiences in the U.S.

14. While in the US, have you been to urgent care or an emergency room in the last 12 months?

- No
- Yes, I have been to urgent care or an emergency room _____ times in the last 12 months.

15. While in the US, have you seen a **doctor or nurse** in an office or clinic in the last 12 months?

- No
- Yes, I have seen a doctor or nurse in an office or clinic _____ times in the last 12 months.

16. Do you have a doctor or nurse that you consider your **“regular”** doctor or nurse?

- No
- Yes

17. How easy or hard is it for you **to describe how you feel** to a doctor or nurse when something is bothering you?

- Very easy
- Easy
- A little hard
- Somewhat hard
- Very hard

18. How easy or hard is it for you **to ask a doctor or nurse questions** about your health?

- Very easy
- Easy
- A little hard
- Somewhat hard
- Very hard

19. How easy or hard is it for you **to tell a doctor or nurse that you don’t understand** what it is they have told you?

- Very easy
- Easy
- A little hard
- Somewhat hard
- Very hard

Please answer every question

ID #: _____

20. Do you know **where to go** if you want to talk with a doctor or nurse about what you can do to **keep yourself healthy**?

- No
- I'm not sure
- Yes

21. When receiving health care in the US, have you ever felt you were discriminated against?

- No
- I'm not sure
- Yes

If yes, what do you think was the reason for the discrimination? (check all that apply)

- Age Skin color Language Weight
- Insurance Income Disability Gender
- Culture Cultural beliefs Other: _____

About your health

22. Do you have any health problems diagnosed by a doctor or nurse?

- No
- Yes

If yes, please check all of the health problems you have:

- Heart attack or heart disease
- High blood pressure
- Stroke
- High cholesterol
- Lung disease (asthma, emphysema, tuberculosis)
- Arthritis
- Cancer: please list what type(s): _____
- Depression, anxiety or other mental or emotional health problem
- Diabetes (high sugar)
- Hepatitis
- Liver disease
- HIV infection or AIDS
- Other: _____

Please answer every question

ID #: _____

23. How would you rate your overall **mental health**?

- Excellent
- Very Good
- Good
- Fair
- Poor

24. How would you rate our overall **physical health**?

- Excellent
- Very good
- Good
- Fair
- Poor

25. How would you rate your **health overall**?

- Excellent
- Very good
- Good
- Fair
- Poor

26. In the past year, how often have you **used alcohol** (for men, 5 or more drinks a day. For women, 4 or more drinks a day)?

- Never
- Once or Twice
- Monthly
- Weekly
- Daily or Almost Daily

27. In the past year, how often have you **used tobacco products**?

- Never
- Once or Twice
- Monthly
- Weekly
- Daily or Almost Daily

28. In the past year, how often have you **used prescription drugs for non-medical reasons**?

- Never
- Once or Twice
- Monthly
- Weekly
- Daily or Almost Daily

Please answer every question

ID #: _____

29. In the past year, how often have you **used illegal drugs**?

- Never
- Once or Twice
- Monthly
- Weekly
- Daily or Almost Daily

General questions about you

30. What is your age (in years)? _____

31. What is your gender?

- Male
- Female
- Transgender

32. What is your marital status?

- Single
- Married
- Widow
- Separated/divorced

33. What kind of health insurance or coverage do you have?

- Private health insurance
- Medicare/Medicaid/MassHealth
- Tri Care through the Veterans Administration (VA)
- Health Safety Net/Free Care
- Other: _____
- I don't know
- I don't have health insurance

34. How many **years** of formal schooling do you have? _____

Please answer every question

ID #: _____

35. What is the **highest level of education** you have **completed**? (*Check one box*)

- Never attended school
- Primary or elementary school
- Junior or secondary or middle school
- Senior secondary or high school
- Some college, Associate Degree or Technical Degree
- Bachelor's Degree
- Graduate Degree (MBA, MD, JD, MS, PhD)

36. About **how many hours** do you **work per week** at all of your jobs and businesses combined? _____

37. At your main job or business, how are you generally paid for the work you do? Are you:

- Paid by salary
- Paid by the hour
- Paid by the job/task (e.g. commission, piecework)
- Paid some other way
- Don't know/Not sure

38. How many people live in your household including yourself? _____

39. What is your **total combined family income** for the past 12 months, before taxes, from all sources, wages, public assistance/benefits, help from relatives, alimony, and so on?

If you don't know your exact income, please estimate.

- Less than \$5,000
- \$5,000 - \$9,999
- \$10,000 - \$14,999
- \$15,000 - \$24,999
- \$20,500 - \$49,999
- \$50,000 - \$99,999
- \$100,000 - \$149,000
- \$150,000 - \$199,999
- \$ 200,000 or more

Thank you!

Appendix C: Newest Vital Sign Form

ID # _____

Newest Vital Sign

Show the following label to the subject and ask the following questions.

READ TO SUBJECT: This information is on the back of a container of a pint of ice cream.

1. If you eat the entire container, how many calories will you eat?

Answer: 1,000 is the only correct answer

2. If you are allowed to eat 60 grams of carbohydrates as a snack, how much ice cream could you have?

Answer: Any of the following is correct: 1 cup (or any amount up to 1 cup), half the container. Note: If patient answers "two servings," ask "How much ice cream would that be if you were to measure it into a bowl?"

3. Your doctor advises you to reduce the amount of saturated fat in your diet. You usually have 42 g of saturated fat each day, which includes one serving of ice cream. If you stop eating ice cream, how many grams of saturated fat would you be consuming each day?

Answer: 33 is the only correct answer

4. If you usually eat 2,500 calories in a day, what percentage of your daily value of calories will you be eating if you eat one serving?

Answer: 10% is the only correct answer

READ TO SUBJECT: Pretend that you are allergic to the following substances: penicillin, peanuts, latex gloves, and bee stings.

5. Is it safe for you to eat this ice cream?

Answer: No

6. (Ask only if the patient responds "no" to question 5): Why not?

Answer: Because it has peanut oil.

The Newest Vital Sign is a validated predictor of health literacy, measuring both literacy and numeracy skills. The NVS consists of a food nutrition label with six associated questions giving scores from 0 to 6.²⁴ It is quick to administer (3 minutes), acceptable to patients, and accurately predicts health literacy levels. Validation testing showed high internal consistency (Cronbach's Alpha = 0.76).

Nutrition Facts		
Serving Size	1/2 cup	
Servings per container	4	
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%
*Percentage 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.		

Appendix D: Freelist Form

H00005931

ID # _____

Freelist Form

<p>When you read the word “healthy”, write down the first 5-10 words (or group of words) that come to mind?</p> <ol style="list-style-type: none">1. _____2. _____3. _____4. _____5. _____6. _____7. _____8. _____9. _____10. _____	<p>When you read the word “primary care”, write down the first 5-10 words (or group of words) that come to mind?</p> <ol style="list-style-type: none">1. _____2. _____3. _____4. _____5. _____6. _____7. _____8. _____9. _____10. _____
<p>When you read the word “prevention”, write down the first 5-10 words (or group of words) that come to mind?</p> <ol style="list-style-type: none">1. _____2. _____3. _____4. _____5. _____6. _____7. _____8. _____9. _____10. _____	<p>When you read the word “risk”, write down the first 5-10 words (or group of words) that come to mind?</p> <ol style="list-style-type: none">1. _____2. _____3. _____4. _____5. _____6. _____7. _____8. _____9. _____10. _____

<p>When you read the word “symptoms”, write down the first 5-10 words (or group of words) that come to mind?</p> <p>1. _____</p> <p>2. _____</p> <p>3. _____</p> <p>4. _____</p> <p>5. _____</p> <p>6. _____</p> <p>7. _____</p> <p>8. _____</p> <p>9. _____</p> <p>10. _____</p>	<p>When you read the word “health insurance”, write down the first 5-10 words (or group of words) that come to mind?</p> <p>1. _____</p> <p>2. _____</p> <p>3. _____</p> <p>4. _____</p> <p>5. _____</p> <p>6. _____</p> <p>7. _____</p> <p>8. _____</p> <p>9. _____</p> <p>10. _____</p>

<p>When you read the word “proactive”, write down the first 5-10 words (or group of words) that come to mind?</p> <p>1. _____</p> <p>2. _____</p> <p>3. _____</p> <p>4. _____</p> <p>5. _____</p> <p>6. _____</p> <p>7. _____</p> <p>8. _____</p> <p>9. _____</p>	<p>When you read the word “clinic”, write down the first 5-10 words (or group of words) that come to mind?</p> <p>1. _____</p> <p>2. _____</p> <p>3. _____</p> <p>4. _____</p> <p>5. _____</p> <p>6. _____</p> <p>7. _____</p> <p>8. _____</p> <p>9. _____</p>
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<p>10. _____</p>	<p>10. _____</p>
<p>When you read the word “screening”, write down the first 5-10 words (or group of words) that come to mind?</p> <p>1. _____</p> <p>2. _____</p> <p>3. _____</p> <p>4. _____</p> <p>5. _____</p> <p>6. _____</p> <p>7. _____</p> <p>8. _____</p> <p>9. _____</p> <p>10. _____</p>	<p>When you read the word “check up”, write down the first 5-10 words (or group of words) that come to mind?</p> <p>1. _____</p> <p>2. _____</p> <p>3. _____</p> <p>4. _____</p> <p>5. _____</p> <p>6. _____</p> <p>7. _____</p> <p>8. _____</p> <p>9. _____</p> <p>10. _____</p>

Thank you