The Importance of Health Literacy in Healthcare and the Identification of Low Health Literacy in a Spanish Speaking Population

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Abstract

Introduction: This thesis determines the importance of health literacy in a modern healthcare setting, discussing how the Spanish-speaking population is disproportionately represented by low health literacy. It shows the connections between low health literacy and health outcomes, all giving reason to conduct a research study identifying low health literacy among a Spanish-speaking population in a healthcare clinic.

Methods: A questionnaire was constructed with a combination of validated survey questions, and some not, to explore different domains of literacy and health literacy. 25 participants were surveyed at the front desk of a clinic.

Results: The different sections of the survey produced inconsistent rates of response. The two core questions had high rates of response, on the first core question about general literacy, 79.1% of participants reported a low level of English proficiency. On the second core question about health literacy, 75% of participants reported low health literacy.

Discussion: The goal of this study was achieved, identifying a high rate of low health literacy, with 75% of the participants self-reporting a health literacy rate categorized as low. Due to the varying validity of individual questions, the study could be improved by validating the entire questionnaire prior to conducting the study, and increasing the sample size. This literature review and study recommends future research about health literacy rates of providers and communication abilities, and differences in terminology within different Spanish dialects.

Introduction

Health literacy is growing in popularity for topics of study throughout recent trends in public health, and can be seen as a “buzz-word” for policy and change, and for good reason[1]. The term health literacy seems to have first been used in the 1970’s and has continued to increase in use[25]. However, the bulk of the current research has been conducted since about 2005. In the early stages of the term, it was more similar to basic literacy, in a sense of having an ability to comprehend and read literature and have a knowledge in medicine to contextualize information. Now health literacy has expanded more to understand that it also includes things like your ability to act on health instructions, interact with your provider, and recently, the potential for health literacy to move beyond an individual characteristic and be an interaction between an individual and other systems. In the 2019 National Action Plan to Improve Health Literacy, Howard K. Koh of the U.S. Department of Health and Human Services (DHHS), Office of Disease Prevention and Health Promotion, defined health literacy as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions”[34]. This action plan informed a large part of this study and research, and because of the accessible nature of information from the DHHS, this definition is frequently used and will be used as the running definition of this study. Alternatively, a literature review conducted by Sorenson et al[25] in 2012 synthesized a definition based on theme analysis within all researched definitions available of health literacy and identified main concepts of health literacy. These concepts held the definition of health literacy to include competencies within these four categories: access, understand, appraise, and apply.

Understanding health literacy and improving it is crucial to the health of our society and equitability throughout our healthcare system for the patients. To advocate for marginalized groups for equitable healthcare is not just advocating for access to care. It is also to advocate for the quality of care received, the ability to be involved in your own healthcare, and to rectify lower health outcomes within marginalized groups that are linked to low health literacy. From a more biological standpoint, the health of a population is part of the sustainability of the population in our society, and we need to continue to support diversity throughout our society[1]. Increasing our total population health is extremely beneficial in multiple sectors, and increasing health literacy is directly tied to that. The World Health Organization (WHO) listed 6 known facts about health literacy, three of which are: high literacy rates in population groups benefits societies, limited health literacy follows a social gradient and can further reinforce existing inequalities, and limited health literacy is associated with high health system costs[1]. Health literacy is another level of intersectionality, low health literacy is damaging and affects minorities more intensely. From a human rights standpoint, these groups deserve support to increase their health, but also it is shown that individuals with higher health literacy are more likely to participate in the economy, and experience better health and well-being, benefitting society as a whole. This is connected to Maslow’s hierarchy of needs which lists health as a primary need, and as previously stated it is not simply access to healthcare but the ability to understand, appraise, and apply health information to live a healthier lifestyle and receive higher quality care. With primary needs met, people are more likely to prosper.

As stated by the WHO report, low health literacy caused $73 billion of additional healthcare costs in 1998[1]. There is minimal research showing a concrete connection between low health literacy improvement and healthcare costs decreasing,[6] however it is shown that increasing preventive care improves health outcomes[22]. Working to increase health literacy of the population is preventive care because people with higher health literacy are less likely to make risky health choices, and it is associated with higher levels of health-promoting activities, better management of chronic diseases, adherence to medication, and many other metrics affecting healthcare outcomes and costs[1]. We have seen an increase of support for this with decreased premiums being offered by healthcare companies for proof of healthy lifestyles and meeting health benchmarks. A study by the Kaiser Family Foundation, a non-profit organization dedicated to providing data and research on national health issues, found that 77% of employers that offered healthcare benefits supplemented that with programs to improve wellness or provide preventive care[22]. In a society looking to be progressive, inclusive, and sustainable, health literacy must be a place of improvement.

Equitable and efficient healthcare are at the forefront of a lot of provider team's minds right now, as gaps in healthcare are realized and we continue to strive to provide the highest level of care as we can to patients[38]. Team-based patient care is becoming more popular as a way to ensure that all sides of healthcare are able to be addressed, together and in a communicative way to effectively prevent, target, treat, and manage a person's issue. Research shows that providers normally do not use techniques that are recommended to use with patients with low health literacy[26]. It is also seen that providers typically list medical counseling patients as a skill, however do not report using it in practice[22]. A common method recommended to ensure understanding of a low health literacy patient, is the teach-back method[8,27]. This allows the patient to repeat the information provided to them, supporting an opportunity for the provider to fix any misinterpreted information and also see that the patient will be able to utilize the information in practice. An example of this would be asking a patient to describe the medication changes being made to their prescription and when they will be taking the new medication. Providers, specifically Medical Doctors, are heavily pushed to see as many patients as possible in a day leaving little time to spend on this level of preventive care, ensuring quality care is given and received. Typically providers report using plain language, speaking slowly, and using printed hand-outs as the most common techniques used to improve the outcome of providing information to someone with low health literacy[26]. A potential way to fill this gap is the utilization of health educators in communities, who's job is to continue to research the needs of the community and difficulties faced trying to reach the community in order to construct plans to effectively communicate health information to the community to combat an issue[4]. The specific role of a health educator in a community is to provide context for people surrounding the importance of certain health activities that the provider may have not been able to explain or lacked the time to, in an effort to improve health outcomes via increase in medicine compliance or lifestyle changes. With the continually increasing population of

Spanish-speakers and hispanic/latinx identifying people in the United States[18], providers and communities must be culturally responsive to the needs of the changing population. The high level of low health literacy among the Spanish-speaking population calls for deeper support in healthcare, promotores de salud, or promotoras, are part of this support. Promotora is the Spanish word for a community health worker which is a similar role to a health educator. There are many national programs and community based programs implemented through the work of promotoras, including an initiative by the DHHS to support the implementation, training, and utilization of them. Promotoras have been extremely useful especially in areas with high populations of Spanish-speaking farm workers, to increase the exposure they have to health-related information. One study showed a decrease in Hemoglobin A1C values for high-risk patients that was correlated to the use of promotoras[11]. Participants in the study also reported feeling more comfortable talking about diabetes and more supported from friends and family.

It is important for healthcare providers in this current society to recognize the importance of being responsive to their patients' needs, abilities, rights, and differences. Most importantly, to lower the barrier created by language, if a provider cannot speak Spanish fluently, it should be expected that the patient is offered a translator, preferably in person[12]. Low English proficiency and low health literacy are not dependent on one another however, they have been shown to be very heavily related when tested functionally[27]. Federally, it is required that an interpreter or translator be used to communicate with patients who speak no or limited English, and using a minor child is prohibited[12]. It is still the patient's choice to accept or decline this service, however there is a high level of stigma and fear involved in using an interpreter in practice today for the patient, and by continuing to offer the service and explaining the use of it, the efficiency and quality of care can be improved.

Providers have to recognize the abilities of their patients in order to provide effective, patient-centered care. Patients with lower health literacy are less likely to report feeling like they receive patient-centered care[1,39]. It has been studied that provider's commonly overestimate the health literacy of their patients, more frequently in minority patients (54% of the time for African-Americans, 36% for other non-white ethnicities, and only 11% of the time for white patients)[14]. It is not recommended that patients be routinely checked for their level of health literacy, but rather that providers consistently use techniques discussed earlier, like the teach-back method[8]. It is also important that information be consistent, this is one of the recommendations in the National Action Plan to Improve Health Literacy, that all medical instructions and information need to be converted into plain, universal language that is closer to the level of the average American reading level, which is around an eighth grade level[34]. By following these universal health literacy precautions, providers can take a step towards providing more patient-centered care and then continue to learn more about each patient's specific needs, regardless of their language, but especially for patients that do not speak English.

As stated earlier, it is not recommended that every patient is routinely tested for health literacy levels, the majority of testing is for research purposes[8]. In research settings, testing has evolved a lot. In the 2003 National Assessment of Adult Literacy (NAAL) there was a section focusing on health literacy[15], however the tasks on this assessment surrounded different themes of health literacy than current definitions support. The three domains focused on were clinical, prevention, and navigation of the healthcare system. While these domains are extremely important factors, these tasks did not include any functional tests of health literacy, with vocabulary or specific knowledge of medical terminology. This is where research metrics have shifted in recent years. Multiple testing tools have been created and validated, the most commonly used is the Test of Functional Health Literacy in Adults (TOFHLA), which has also been adapted to be shorter, the STOFHLA, another similar test is the Rapid Estimate of Adult Literacy in Medicine (REALM)[19]. These tests are focused around medical terminology and identification of vocabulary, typically in a flashcard type format. These tests also only focus on functional health literacy. A validated and frequently used test for self-reported, qualitative health literacy metrics is the Single Item Literacy Screener (SILS) question,[21] which reads, “How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?”, in order to easily identify people who may need help with print health information. Current research is pushing for a combination of the questions on the NAAL, SILS, and the functional tests, to test for skill-based application of health literacy[30], which is more closely aligned with current definitions of health literacy. There is also a need for more translations of these testing tools, and tools that originate in other languages. The TOFHLA has a Spanish version[30], TOFHLA-SPR, which has been shown to be valid in Spanish communities in Puerto Rico[25]. There is also a Spanish origin test, the Short Assessment of Health Literacy for Spanish Adults (SAHLSA-50) which was based on the REALM test and when tested against the TOFHLA-SPR showed valid results[5].

In order to use a team-based patient care method most effectively, the patient needs to be thought of as part of this team as well. This study aims to highlight a gap in patient education, which limits the patient's ability to participate in their own healthcare, which can ultimately lower the effectiveness of healthcare[1,38-39]. The importance of this study is to identify the disparity Spanish-speaking patients are facing, first, as a crucial, initial step before trying to fix the problem. In order to close the gap, it needs to be visualized first. In the 2003 National Assessment of Adult Literacy[15], it showed that the hispanic/latinx population was overrepresented for having the highest rate of low health literacy in comparison to the percentage that group represents in the population. This study also showed that as self-reported health ratings dropped, the average health literacy within the group was also lower. While this does not determine a causal link between the two, it does show a trend between low health literacy rates and low self-reported health ratings. Sentell T, Braun KL[27] showed in California that 44.9% of people surveyed with low English proficiency also identified with low health literacy, specifically, 45.3% of participants also identifying as Latino identified having a low health literacy rate. This study also showed that participants that reported low English proficiency and limited health literacy, also had the highest rate of poor health, at 45.1% of these participants. It has been difficult to find a direct causal link between low health literacy and reports of poor health[1,22,27,34], however as stated earlier, the issue of health literacy is incredibly intersectional to begin with, having many factors that cause it and that increase the effect it will have on a patient's health. Income, education level, culture, and other factors all affect and combine to determine a person's health literacy and ability to change it[1]. Wynia M, Osborn C[39] researched if a relationship between health literacy and provider-patient communication was seen. It was reported that patients with lower health literacy were less likely to say that they always received patient-centered care and communication, which is one of the common goals of providers and healthcare teams. By identifying a need for improvement, further research can be conducted to improve the care provided to these patients, holistically.

The National Action Plan to Improve Health Literacy outlines many of the ways limited health literacy negatively affects healthcare, but first starts by identifying the demographic of the population that is facing limited health literacy[34]. This shows that the core piece of improving health literacy is first identifying it and understanding the specific needs of the population you are working with. I have seen firsthand in multiple clinics how hard it is for healthcare workers to ask a patient's level of literacy or if they need help, and also how infrequent it is for a patient to openly disclose this information without provocation. By allowing the participants to use an anonymous survey, it will be less invasive and easier to see the demographic within this clinic to more deeply analyze the problem. Even in a setting with access to bilingual providers and information, the barrier still remains and it is important to recognize and identify the disparity these patients are facing.

Methods

Context

The study was set up for October 14th and 15th, 2019 at a clinic that "serves a high-need community (designated a Medically Underserved Area or Population)" and also hosts a staff of bilingual providers to serve patients who are Spanish speaking[F1].

Design

For this quantitative study, a cross-sectional survey[37] was used to obtain multiple self-reported values surrounding health literacy and other issues in multilingual healthcare. The informed consent for this study was a template created by Appalachian State University and then modified and translated to fit the study. The informed consent was also peer and faculty reviewed for correctness and effectiveness. An interview guide was also created for a proposed interview with providers at the clinic research was conducted at, however the lead provider at the clinic said it was highly unlikely that time would be available to interview the providers for the proposed amount of time during a clinic day.

Sampling

The sampling method used was convenience sampling, as the clinic utilized was known to serve a high number of native Spanish-speakers and the principal investigator did not randomly choose participants. The inclusion factor for the study was that the participant had to be a native Spanish-speaker. This was determined during the check-in process at the front of the clinic and assessed again in the survey to ensure

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[1] A source is unable to be cited with this quote to keep the clinic/research site anonymous.

accuracy. The clinic has a high patient load, therefore the check in process is typically very fast. In order to not interrupt the flow of the clinic, the principal investigator sat at the front desk of the clinic and while patient check ins were being finalized, gave a small introduction to the study and offered the patient to participate, if they were Spanish speaking. If the patient agreed to participate, the principal investigator handed the participant a clipboard with the informed consent and the survey attached and instructed them to fill it out while sitting in the waiting area. There were multiple desks in the front of the clinic serving multiple patients at a time, if a potential participant was unable to be talked to at the front desk, the principal investigator would approach them in the waiting room and give the same introduction and offer to participate. To avoid selection bias, the principal investigator offered any patient that spoke Spanish to participate in the survey. In order to maintain a safe environment for the patients while in a healthcare setting, during the introduction and on the informed consent it was stated that the survey would not be shared with their provider, was anonymous, and not required. The principal investigator did not have training or experience with participant sampling, however the principal investigator did have experience communicating with Spanish-speaking patients at this clinic prior to the study. At the end of the two days of research, a total of 25 surveys had been filled out. Because this survey was only conducted over two days, not all Spanish-speakers that attend the clinic were surveyed, only the Spanish-speakers who were present during that day had the opportunity to participate.

Questionnaire

In order to create the most effective survey without performing pre-testing or other validity tests, information and questions were pulled from other reputable sources and surveys in Spanish. The first half of the survey was demographic style questions and questions about the participants Spanish literacy level and English proficiency (see Appendix). The demographic questions and responses were pulled from the Census Bureau survey about the American community, which was available in Spanish[35,40]. The following questions about general literacy were based on questions typically asked in schools to gain information about English Language Learners[10]. The two core questions of the survey were pre-validated in other studies. The first core question was for self-reported English literacy levels, which was shown to be a valid measure in the Census Bureau survey[35,40]. The second half of the survey was focused on health literacy and the participant's level of confidence in their healthcare abilities. The second core question is a translated version of the SILS, which is also a validated measure for self-reported health literacy[21]. The following supplemental health literacy questions were also based on pre-tested brief questions to get information on different competencies of health literacy, however these brief questions had been shown to be more effective at identifying inadequate levels of literacy, and less effective in marginal levels of literacy[3]. The themes focused on when asking about health literacy were based on common themes determined by Sorenson et al[29] of "access, understand, appraise, and apply". A question was constructed to address each of these themes individually. The survey was initially written in English to be submitted to the IRB, but was then translated into

Spanish before research was conducted. When translating, the scales and options used were researched and the most commonly used response phrases and options were used[25,40]. The translation was peer and faculty reviewed by a student and professor from the Spanish department of Appalachian State University to check for correctness and effectiveness of the language. There are many tested tools for testing health literacy quantitatively using vocabulary and other metrics, however qualitatively, there are a few very specific questions to target self-reported health literacy. These questions were used or slightly modified, and it was attempted to maintain the integrity of the questions throughout translation.

Data collection

The study was approved via the Appalachian State University Institutional Review Board (IRB) (Study 20-0003) and was considered exempt due to the nature of the study having minimal to no risk of harm to the participants (see Appendix). As stated above, participants were selected and immediately given the informed consent and survey to fill out. For the majority of the studies the participant was able to finish the survey before being called back to an exam room, but occasionally the survey was not completed and the participant would return the survey after the visit was completed. During the introduction every patient was informed that if they had any questions or needed any help the principal investigator would be available, however this was very rarely utilized. On one occurence a participant expressed not being literate in Spanish and needed the questions read aloud, which the principal investigator did. After a survey and signed informed consent was returned, they were placed into an envelope that only the principal investigator had access to. Of the 25 surveys, the overall response rate was 100%, however one of the sets of responses was considered no response as the survey paper returned had been written on by a child during the office visit and the responses were now illegible. This made the available data set 96% of the sample set and 24 sets of usable data in total. Not all of the questions on every survey was answered, this will be discussed further in the results section.

Data analysis

The surveys were then separated from the informed consent forms to maintain anonymity. To analyze the data each survey was numbered and specific questions were input into an excel spreadsheet with corresponding answers for each survey. This random numbering maintained the anonymity of each participant, along with the informed consent being kept separate from the survey. The first four questions were simply demographic information to ensure the participants were native Spanish-speakers, gain some understanding about their experience with Spanish and English, and also to orient the participants to the survey questions and theme and give them some context outside of the introduction. Two questions were considered the core questions, giving the most insight into the participants English proficiency and their health literacy. These questions were question 6 of the demographic section and question 1 of the health literacy section. These were the values seen as most important, but responses to questions 5 and 6 of the demographic section and all of the questions in the health literacy section were recorded in an excel document to analyze the data. The majority of the questions were on a likert scale, and a response of “3” or lower on the scale was the threshold to group responses together for trends in the data. General percentages were the main calculations used to provide simple representations of how many participants self-reported being below the threshold of each variable, typically “low” in the category. Qualitative correlations were also made between different variables and calculations, which was considered ethical because the data sets individually have no descriptors of the participant. Missing data will be further discussed in the results and discussion section. A complete case analysis was not used for missing data because it was typically seen that the data was “missing at random” (MAR) or “missing not at random” (MNAR)[24]. Not using these sets of data due to data being missing could have presented biased results. It also would have limited the inferences that were made taking into account the missing data, and the possibility of the missing data being dependent on other variables in the questionnaire. Also, the context of the study provided reasoning to include the missing data considering the goal of the study was to identify health literacy rates among Spanish-speakers and any missing data has a direct impact on the results and inferences made from the data.

Results

For the majority of the survey questions, the data was put into simple percentages, displayed as a pie chart, as opposed to quantities of responses to show trends in responses and also give more value to no response data points. The percentage allows the results to be more applicable to a population as opposed to an arbitrary number of responses that mainly corresponds to the sample size alone.

Statistically, the unit is each participant, these participants were sampled from one collection unit, being the clinic.

In total, 25 surveys were returned, 24 with viable data. This produced a possibility of 360 units of data. 45 units of data were considered missing data, or no response and 4 units of data were considered “write-in” responses, meaning they were not following the provided options on the survey.

Demographics

Demographics were first analyzed to show the population as Spanish speaking or identifying as hispanic/latinx race/ethnic origin. 95.5% of participants identified as hispanic/latinx and 4.5%, 1 participant, yielded no response to the question (see Figure 1). Continuing the demographic identification, 66.7% of the participants said yes they were a native Spanish-speaker, 20.8% said they were not, and 12.5% did not yield a response to the question (see Figure 2).

As mentioned in the methods, missing data, or “no response” as it is categorized here, was included because of the value these trends could hold in regards to health literacy. This is also why someone who did not self identify as a native Spanish-speaker was not excluded from the study or results, because of other outside factors potentially affecting the results. Identifying as either hispanic/latinx and/or being a native Spanish-speaker was included considering these two demographics are not necessarily dependent on each other.

The next three questions represent data used to understand more about the participants' use of Spanish and self-reported literacy, and also to give context for themes in the study. 79.2% of participants reported being able to understand spoken spanish, speak, read, and write Spanish, 8.3% reported being able to speak Spanish, 4.2% can speak, read, and write Spanish, 4.2% can speak and understand spoken Spanish, and 4.2%, 1 participant, did not respond (see Figure 3). 70.8% of participants reported not speaking another language, 12.5% said they spoke English, another 12.5% said they spoke a little English, 4.2%, 1 participant, stated they spoke “dialecto” (see Figure 4). The languages used in different settings had a variety of responses, 33.3% of participants reported using Spanish at home, with friends and with family, 25.0% only answered using Spanish at home and did not respond to the other settings, 29.2% reported multiple languages between the setting, the most common being Spanish and English in different combinations (see Figure 5).

Literacy

The mid-section of the survey was focused on basic literacy and English proficiency of the participants. The next three sets of data represent the specific supplemental questions about the participants’ English abilities as each of these abilities will affect their self-reported literacy and experience in healthcare very differently. This was one question broken up into 3 parts, participants reported their comfort level speaking English with 29.2% saying it was inconsistent, 16.7% saying it was good, 8.2% saying they couldn’t at all, only 4.2%, 1 participant, said very good, and 41.7% of the participants either did not respond or wrote in a response not on the scale (see Figure 6). The second part of the question asked about their comfort reading English, 25.0% reported it being inconsistent, 12.5% said they couldn’t read it at all, 8.3% said their abilities were very good, 4.2% said good, and 50% of the participants either did not respond or wrote in a response not on the scale (see Figure 7). Lastly, participants answered how comfortable they were with their English writing abilities. 20.8% said their writing abilities were inconsistent, 20.8% also said they couldn't write at all, 8.3% said their abilities were very good, and 50% of the participants either did not respond or wrote in a response not on the scale (see Figure 8).

Next the first core question was asked, which identified their self-reported English literacy level or proficiency. On a scale of 1-5, 1 being the lowest and 5 being the highest ability, 33.3% of the participants ranked their general English proficiency at a 1. 25.0% ranked their abilities a 2, 20.8% ranked a 3, 12.5% a 4, 4.2% a 5, and 4.2%, 1 participant did not respond (see Figure 9). Due to this being a core question, a few more statistics were determined from the data. The mean, or average of the data set was 2.26 and 79.1% of the participants reported their abilities at a 3 or lower, which for this study using versions of a Likert scale, a "3" or lower was considered self-reporting low English proficiency.

Health Literacy

The primary goal of the research study was to identify low health literacy among Spanish-speaking patients at this clinic. One question has been used to qualitatively and quantitatively determine this, that is why this next question is another core question of this study. This question asked how frequently the participants needed help with healthcare information. 54.2% of participants reported needing help sometimes, 12.5% said they always need help, 12.5% also said they never need help, 8.3% said they need help frequently, 8.3% also said they almost never need help, and 4.2%, 1 participant did not yield a response (see Figure 10). Using the "3" and under Likert scale guide again, "sometimes" and more would be considered low health literacy, 75% of participants responded with "sometimes" or a higher need. Each option on the scale was assigned a number in line with a numbered Likert scale, "always" being 1 to "never" being 5 and the rest to follow. Using this numerical assignment to calculate a mean, the mean of this data set was 2.875, identifying a mean in between "sometimes" and "frequently".

The following three questions are to gather further information about different aspects of health literacy to show areas of need and allow participants multiple opportunities to disclose their needs and abilities. The first supplemental question asked about the participants ability to understand and manage their health. A 1 was "low confidence" with a 5 being "high confidence". 50% of the participants rated their abilities at a 5, 20.8% rated it at a 3, 12.5% responded with a level of 4, 8.3% at a 2, 4.2% at a 1, and 4.2%, 1 participant, did not yield a response to this question (see Figure 11). The second supplemental question focused on communication abilities with the participant's provider. The same 1-5 scale was used, 33.3% reported 5's or high confidence communicating about their health with their provider, 29.2% rated their confidence a 4, 20.8% responded with a 3, 8.3% a 2, 8.3%, 2 participants, did not respond and no participants rated their confidence at a level of 1 (see Figure 12). The last supplemental question specifically asked if the participants understood all of their prescriptions and other medical instructions and response options were limited to yes, no, and unsure. 79.2% of participants responded, yes they understood all their prescriptions, 0 participants responded no, 12.5% responded that they were unsure, and 8.3%, 2 participants, did not respond to this question (see Figure 13).

Additional/Extra Data

Throughout the study responses, participants wrote in answers to the questions, and at the end of the questionnaire there was an open ended question asking if participants had any areas they needed additional support on or could expand on any answers, these extra pieces of data will be provided here.

-In the demographic section of the survey, one participant responded to both the question asking if they spoke any additional languages, and what language they spoke in different contexts, with “Dialecto” which directly translates to dialect in English.

-Two responses were received to the open ended question at the end of the questionnaire:

“En consultas cuando no hay quien hable espanol”

Which could translate to, [in consultations when there isn’t anyone who speaks Spanish].

“Terminos medicos me cuesta entender, y le tengo que decir a mi hija que me explique”

Which could translate to, [Medical terms are hard for me to understand and I have to tell my daughter to explain].

Discussion

The purpose of this study was to identify low health literacy among a population of Spanish-speakers at the clinic. Overall, this was achieved through quantitative measures that were descriptive and self-reported. The core question that would determine a participant as having a low health literacy, gave results showing 75% of participants self-reported their health literacy within the range categorizing them as having a low health literacy rate. Throughout the study effectiveness and response rate of the questions varied greatly, leading to areas of improvement and further research in this topic.

Breaking the sections of the study down, each section had its own challenges and successes that manifested differently in the data. The demographic questions had strong response rates, however the answers were surprising. It was not expected that only 66.7% of participants would identify as a native Spanish-speaker. However, 95.5% identified as hispanic/latinx. It could be assumed that the phrasing of “native Spanish-speaker” may have been confused with being from a Spanish-speaking country, or something more complex. However, it was confirmed by this study that the majority of participants do not speak English, or another language, 70.8% of the participants responded no to this question. This question and the next open ended question did create some difficulties through the data however. One participant answered yes to speaking another language and used the word “dialecto” which translates to dialect in English. It could be inferred that this means they speak a more specific dialect of Spanish, which could pose a problem in a clinic with information in formal Spanish. This difficulty of interpretation continued throughout the open ended questions, in question 4, participants would sometimes only answer “espanol” for the first blank, but would not answer the question for the other blanks. It was not possible to discern if the answer was meant to apply to all the blanks or not, and made the benefit of an interview, or having the ability to interact more with the participants, clear.

The literacy section of questions represented different issues. It was difficult to make clear conclusions from this section of data because of the high rate of missing data. Each question regarding specific English abilities had a 33.3% no response rate or higher, leading the validity of the questions to be low (see Table 1). However, the following question was studied and validated in prior studies[35,40], it was much simpler and only had one participant not yield a response. Luckily, this allowed for it to be determined that the population of patients being studied demonstrated low self-reported english proficiency rates. The validity in the conclusion was validated by the consistent response in the previous section, 25% of the participants reported being able to speak any English, which validated 79.1% of the participants reporting a low English proficiency rate, despite having some conflicting data in other less valid and effective questions of the survey. This was the first core question of the survey, which yielded the expected results and achieved the secondary goal of the study.

The last section of the survey focused on health literacy and also had mixed results. Similar to the section on literacy, the main core question had been researched and validated in other studies prior to this one and this allowed the study to produce valid and reliable results to make conclusions from[21]. This question was the basic question to determine, descriptively, if someone had a low health literacy rate, by asking how frequently they needed help with health information. The responses showed that 75% of the participants needed help “sometimes” or more frequently. Again, this question only had 1 participant not yield a response, giving a very large sample pool to analyze. This question alone represents that the population is at risk due to having a low health literacy rate and needs increased assistance in healthcare, resource allocation, accessibility, and availability should be priorities. The following questions did not yield results that were supportive of this claim, however these questions we're not tested prior to the study and we're derived from a combination of sources on testing health literacy. One of the sources also explains that these brief questions are most effective at testing inadequate health literacy and not effective at testing for marginal health literacy, which may have caused the conflicting results as well[3]. The conflicting results draw into question the validity of the following questions considering they are simply more specific versions of the general health literacy question, however the response was extremely different. The health literacy portion of the survey also included an open response opportunity for participants to expand upon any answers or express additional support or needs they have, the two responses received were listed and translated in the results section. These two responses were summative of this entire study and gave a great outlook directly into the problems faced by Spanish-speakers in the healthcare system in the United States. The first response stated that the participant needed more support when there isn't anyone available that speaks Spanish during their medical consultations. This lack of access causes a gap in the quality of care able to be provided to this patient and exacerbates the effects of the high rate of low health literacy rates among Spanish-speakers even more[1,12,39]. Following this, the second response was specifically relating to how low health literacy negatively affects healthcare provided. The participant said they have trouble understanding medical terminology so they have to ask their daughter to translate these terms, as opposed to having a provider or certified translator to provide that service and care for them, ensuring that information provided is accurate and understood by the patient[12].

This study provided the desired conclusions, however more descriptive data could have potentially been obtained with changes to the study methods. One method that could be added in the future is the option to debrief with participants after the questionnaire is finished in case any answers are unclear, to ensure the most usable data possible is obtained and no responses are unused or misinterpreted. In order to decrease the rate of missing data/no responses, the questionnaire or specific questions could have been tested prior to the start of the study to find and edit any places of confusion or difficulties, again to produce the highest amount of usable data. Additionally, to improve the translation of the questionnaire, it would be more effective to provide a native speaker the English questionnaire and have them translate it, in order to get a translation that functions better for native speakers. This would also align with the requirements of translators, being that someone cannot be a professional translator typically without being an identified native speaker of the language. Lastly, one major improvement for this study would be to increase the sample size. This would improve multiple aspects of this study, by visiting the clinic on more days it would provide more Spanish-speaking patients the opportunity to participate, and by having a larger sample size the data would be more distinguished and less affected by missing data. This change would allow the conclusions and sample to be more generalizable to the whole clinic’s population and not just the population the sample describes, which is more specific and not random.

Considering the small scale of this study, there is a lot of space for future research to be conducted, and the conclusions and review of literature prior to this, call for future research. A more strongly quantitative aspect could be added to this study, now that a high rate of low health literacy has been determined, to put an actual number to that low health literacy[30]. There are many validated questionnaires specifically for Spanish health literacy testing, the funding just wasn’t available to purchase those for this study, however that information would greatly benefit the study and the clinic. Another extremely needed line of research in relation to this study would be to study the health literacy of providers in their second language[36]. This is important to ensure that providers are also able to effectively communicate with their patients, as it is a two sided conversation and the reception of the information is extremely important. This is definitely not a test of their medical knowledge, but their ability to communicate this information to someone who is not also a doctor and to recognize misinformation, confusion, and also understanding. Healthcare providers are the teachers to their patients and we have to make sure they have the resources and training needed available to them as well to allow them to be effective providers to all groups. Lastly, the knowledge of the abundance of different dialects of Spanish also opens more research to be done within those dialects and how health literacy and medical terms live among different dialects in Spanish. Research could be conducted at multiple levels, including investigating what words are used to describe health literacy, the direct translation “alfabetización de salud” seemed extremely academic and sometimes unknown to Spanish-speakers during research conduction of this study. This research could also lead to more thorough research of different medical terminology in Spanish dialects to better inform medical information being created and translated into Spanish.

Conclusion

Low health literacy is an intersectional issue that disproportionately affects the Spanish-speaking community in the U.S[1,15,27]. In order for providers to deliver high quality, equitable care, it should be expected and supported that providers work to be culturally responsive to this population and in general, follow universal low health literacy precautions when providing care and information[8,34,38]. Improving the health literacy of a society is part of sustaining a strong, healthy, and engaged population and research indicates that health literacy is a place the U.S. should focus on, especially with a continuously growing population of Spanish-speakers[1,18].

In a study conducted in a healthcare clinic providing care to Spanish-speakers and a medically underserved population, 75% of the participants self-reported a low health literacy rate. This study identifies a large area for improvement, in a clinic that already offers bilingual providers and many other resources, the gap in health literacy facing this marginalized group is still extremely visible. Health literacy can be affected by many other aspects including income, education, and culture[1], however, a patient’s race or ethnic origin should not determine their access to high quality, equitable healthcare. We must continue to work to minimize the language and access barrier in healthcare to advocate for these patients and the health of the people in our society.

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Appendix

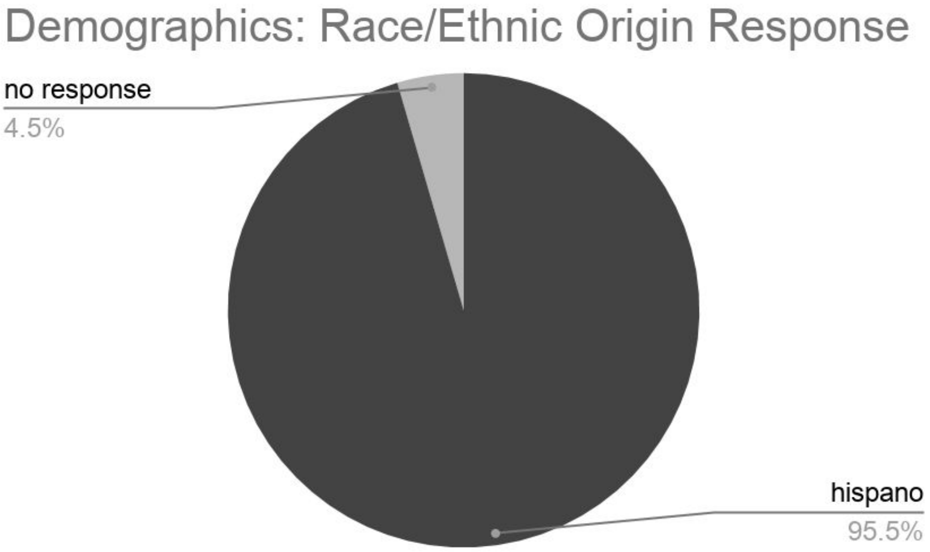


Figure 1. Response percentages to Demographics question for race/ethnic origin identification

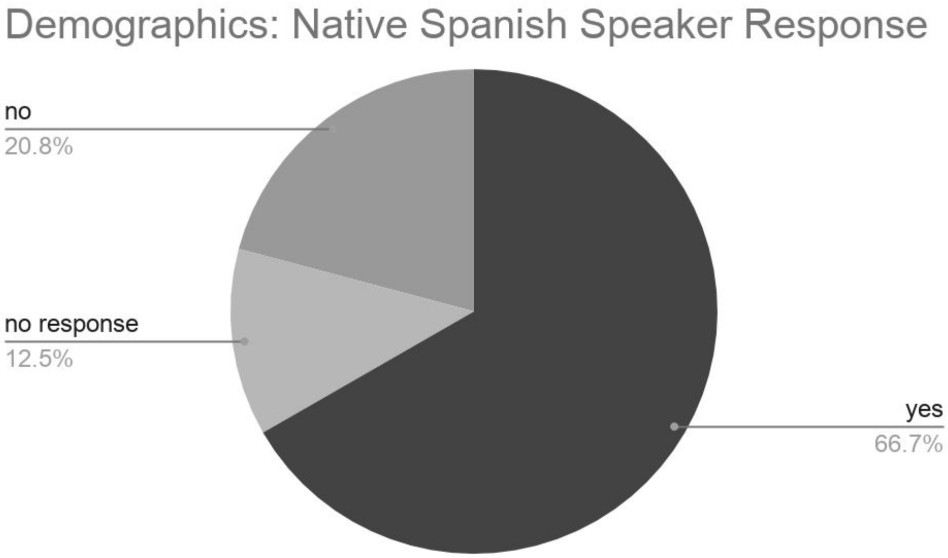


Figure 2. Response percentages for Demographics question for native Spanish-speaker identification

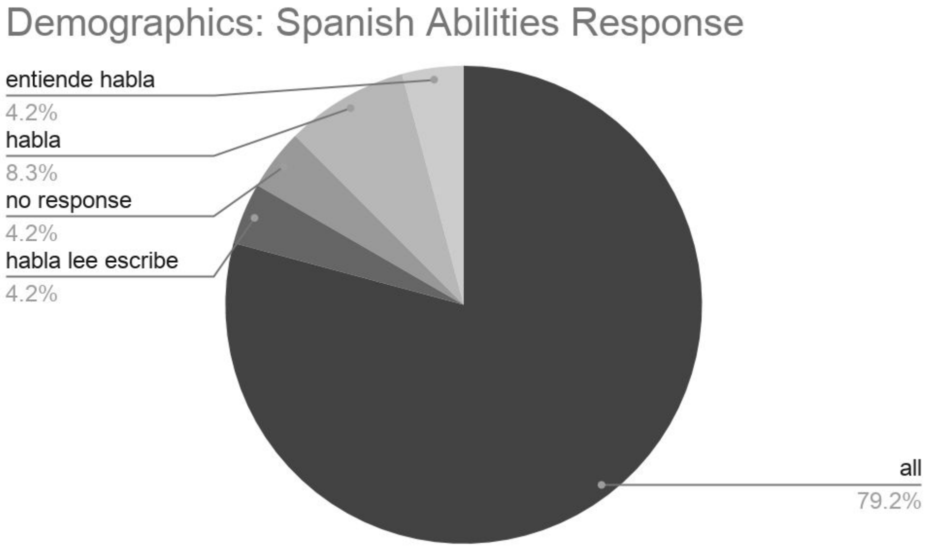


Figure 3. Response percentages to the Demographics question about general Spanish abilities, ability to understand spoken Spanish, speak, read, and write Spanish

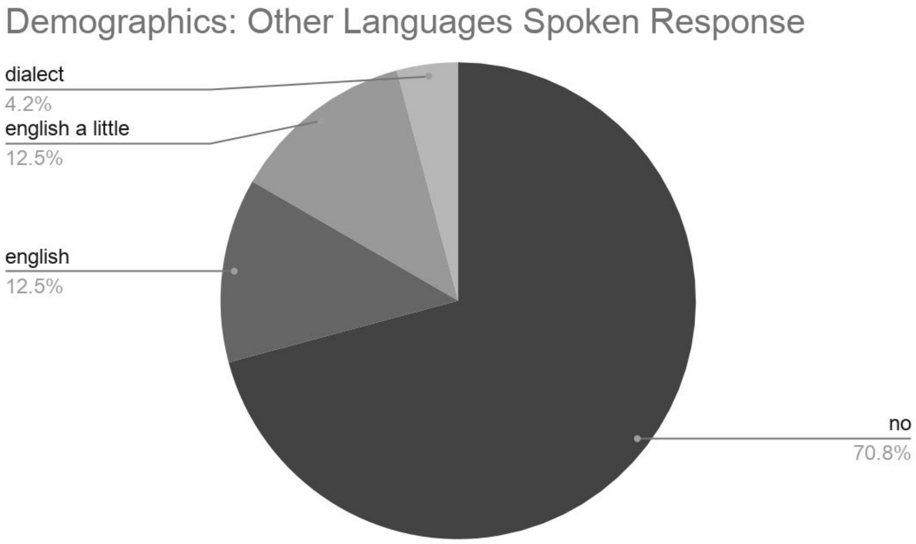


Figure 4. Response percentages to Demographics question about any other languages spoken

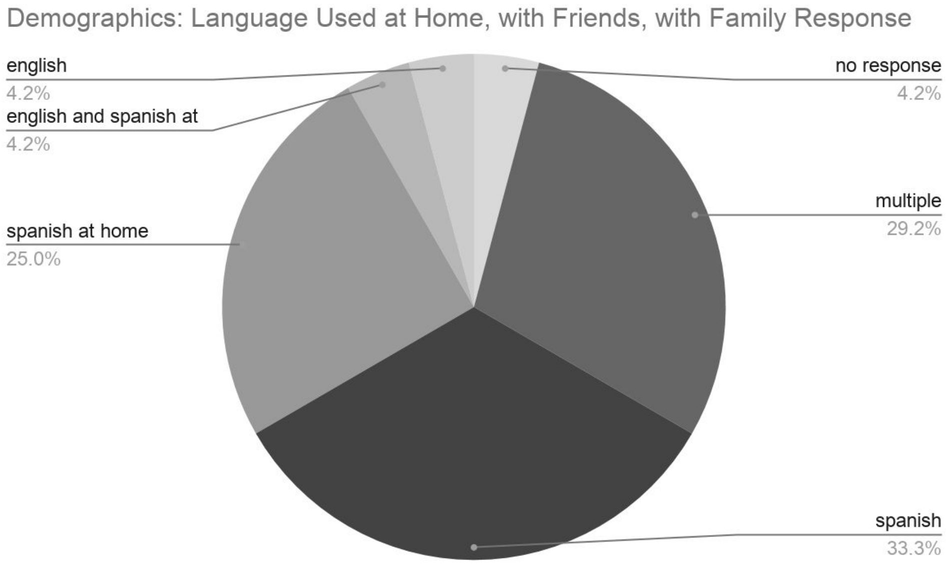


Figure 5. Response percentages to Demographics question about what language is used in different contexts

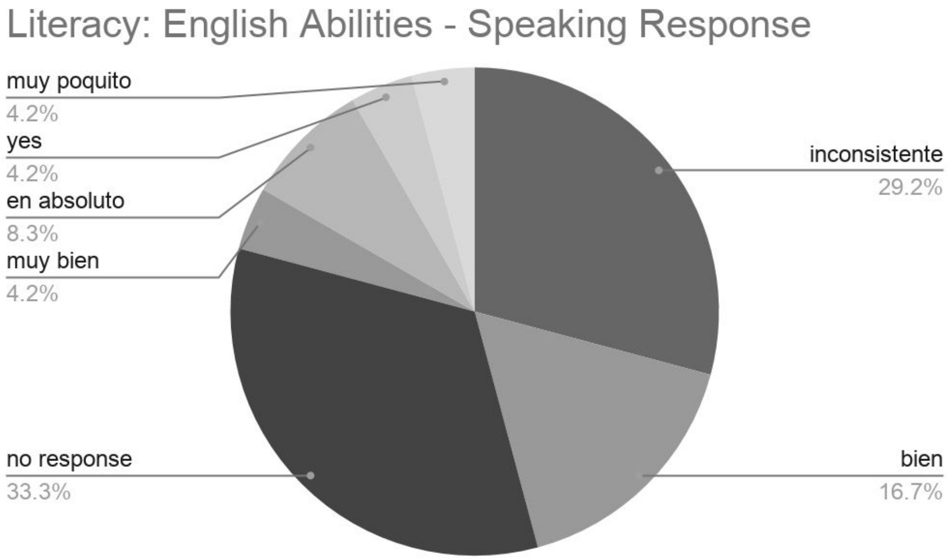


Figure 6. Response percentages to Literacy English speaking abilities question

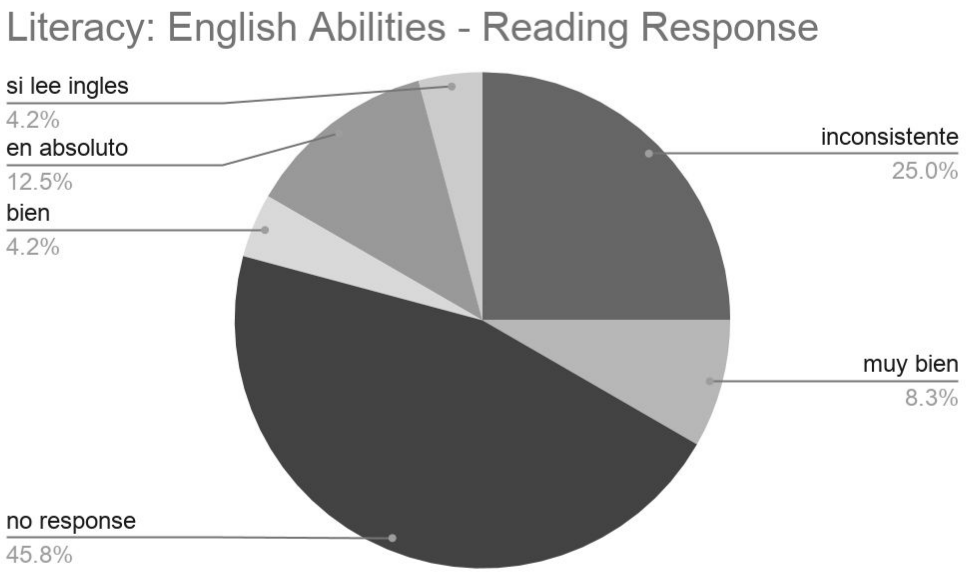


Figure 7. Response percentages to Literacy English reading abilities question

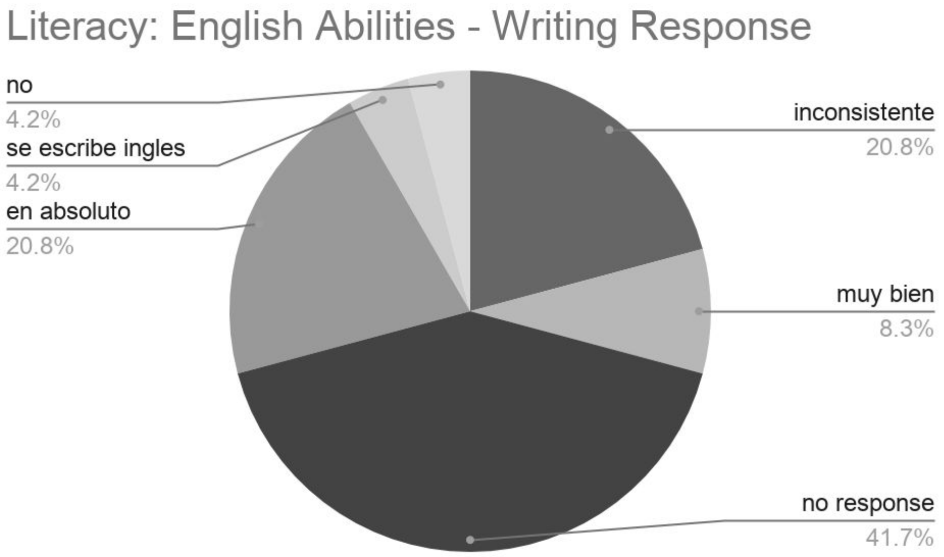


Figure 8. Response percentages to Literacy English writing abilities question

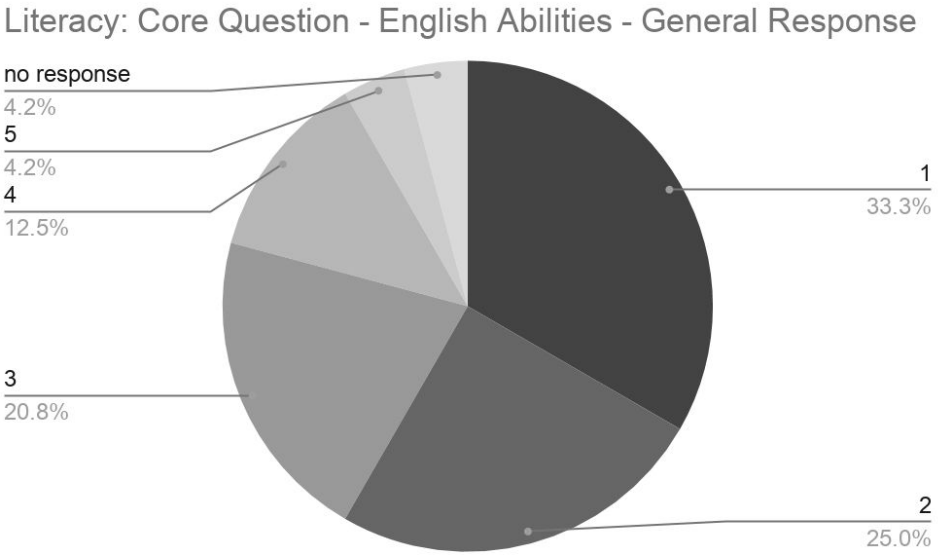


Figure 9. Response percentages to Literacy Core Question, general abilities with English

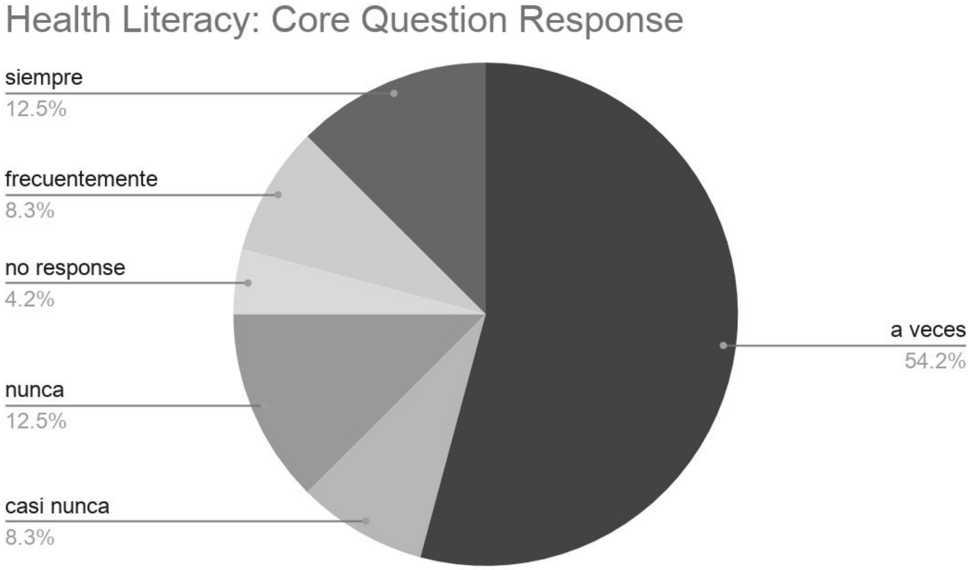


Figure 10. Response percentages to Health Literacy Core Question, how often help needed with medical information, Single Item Literacy Screener

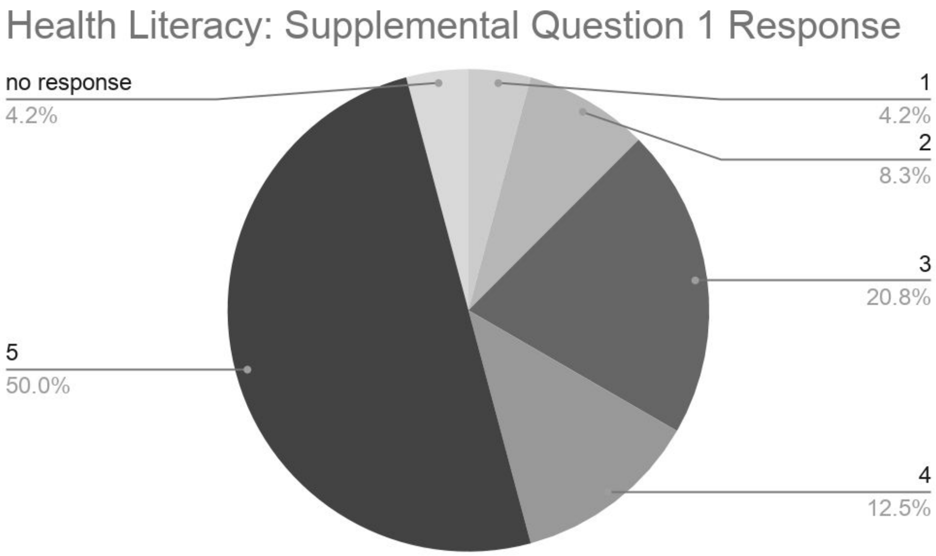


Figure 11. Response percentages to Health Literacy Supplemental question 1, confidence to understand and manage health concerns

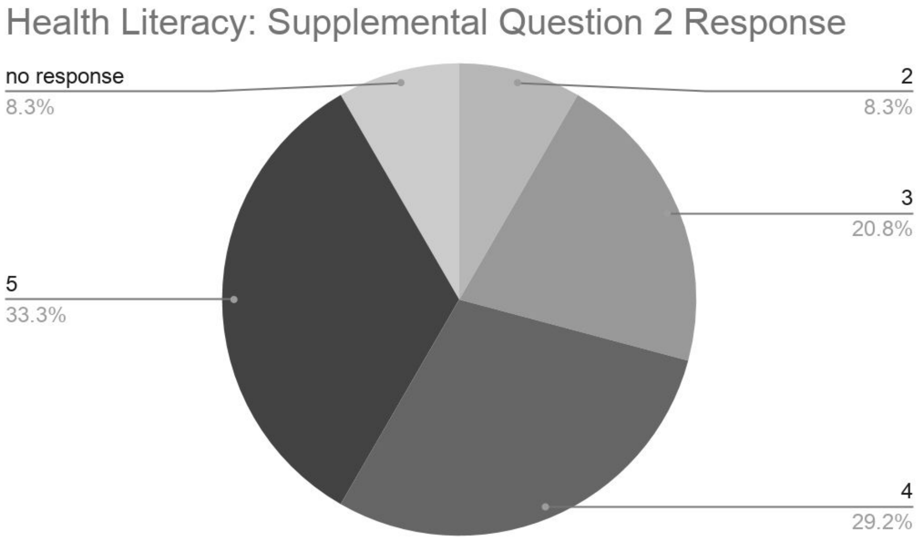


Figure 12. Response percentages to Health Literacy Supplemental question 2, comfort engaging with provider

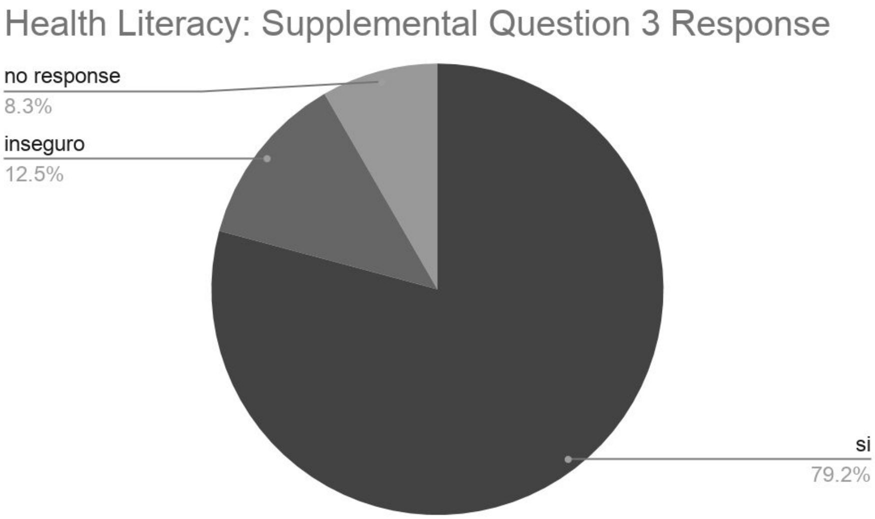
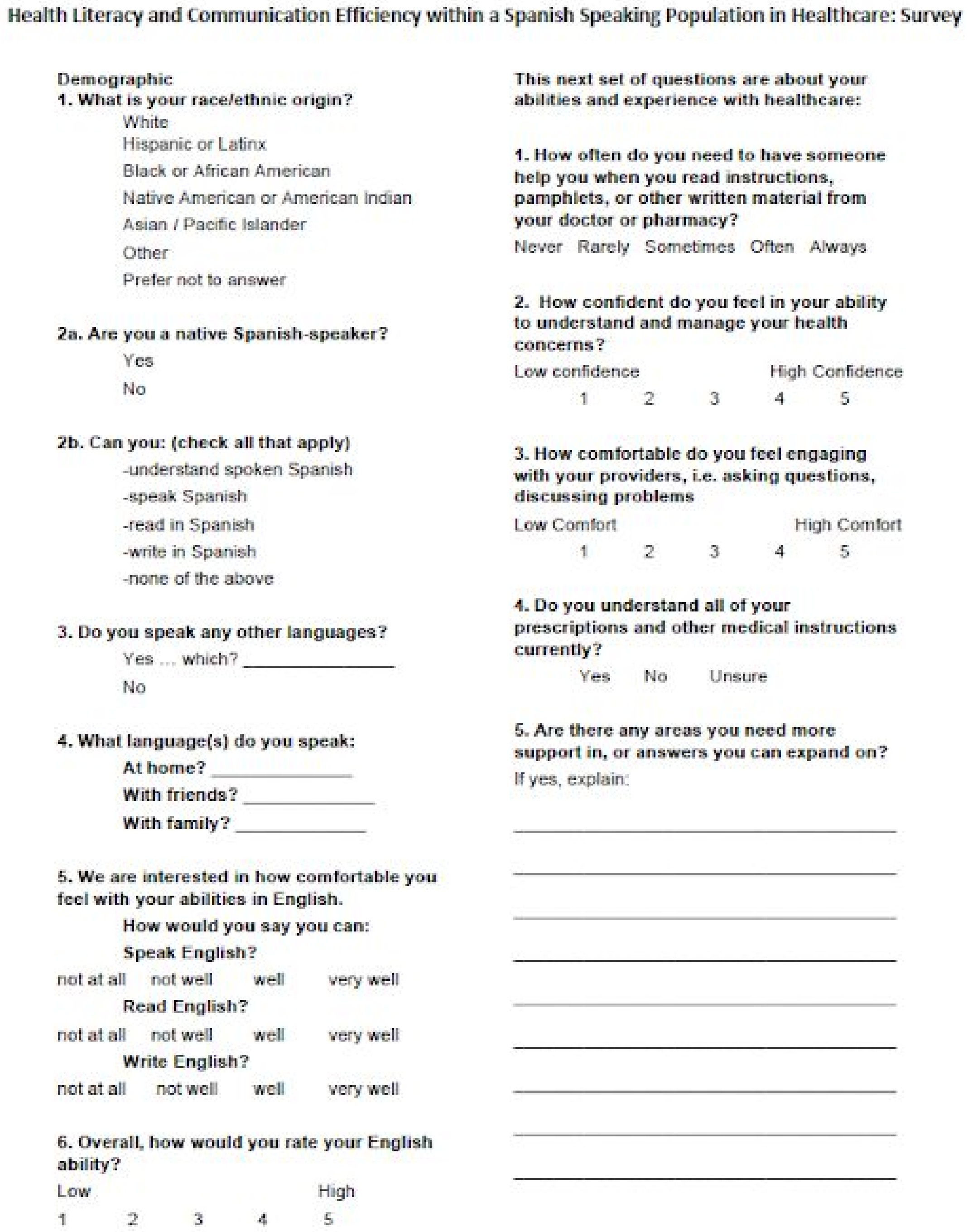


Figure 13. Response percentages to Health Literacy Supplemental question 3, understanding of prescriptions and medical instructions

Table 1	**"No Response" Rate (percentages)**	
Demographics	**Avg: 5.02%**	**Total**
Native Speaker	4.2%	**Avg: 13.47%**
Race/Ethnic Origin	12.5%	
Spanish Abilities	4.2%	
Other Languages	0%	
Other Contexts	4.2%	
Literacy	**Avg: 31.25%**	
Speaking	33.3%	
Reading	45.8%	
Writing	41.7%	
Core: General	**4.2%**	
Health Literacy	**Avg: 6.25%**	
Core: General	**4.2%**	
Suppl. 1	4.2%	
Suppl. 2	8.3%	
Suppl. 3	8.3%	



Health Literacy and Communication Efficiency within a Spanish Speaking Population in Healthcare: Survey

Demographic

1. What is your race/ethnic origin?

White
Hispanic or Latinx
Black or African American
Native American or American Indian
Asian / Pacific Islander
Other
Prefer not to answer

2a. Are you a native Spanish-speaker?

Yes
No

2b. Can you: (check all that apply)

-understand spoken Spanish
-speak Spanish
-read in Spanish
-write in Spanish
-none of the above

3. Do you speak any other languages?

Yes … which? _______________
No

4. What language(s) do you speak:

At home? ______________
With friends? ____________
With family? ____________

5. We are interested in how comfortable you feel with your abilities in English.

How would you say you can:

Speak English?
not at all not well well very well
Read English?
not at all not well well very well
Write English?
not at all not well well very well

6. Overall, how would you rate your English ability?

Low High
1 2 3 4 5

This next set of questions are about your abilities and experience with healthcare:

1. How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?

Never Rarely Sometimes Often Always

2. How confident do you feel in your ability to understand and manage your health concerns?

Low confidence High Confidence
1 2 3 4 5

3. How comfortable do you feel engaging with your providers, i.e. asking questions, discussing problems

Low Comfort High Comfort
1 2 3 4 5

4. Do you understand all of your prescriptions and other medical instructions currently?

Yes No Unsure

5. Are there any areas you need more support in, or answers you can expand on?

If yes, explain:

____
____
____
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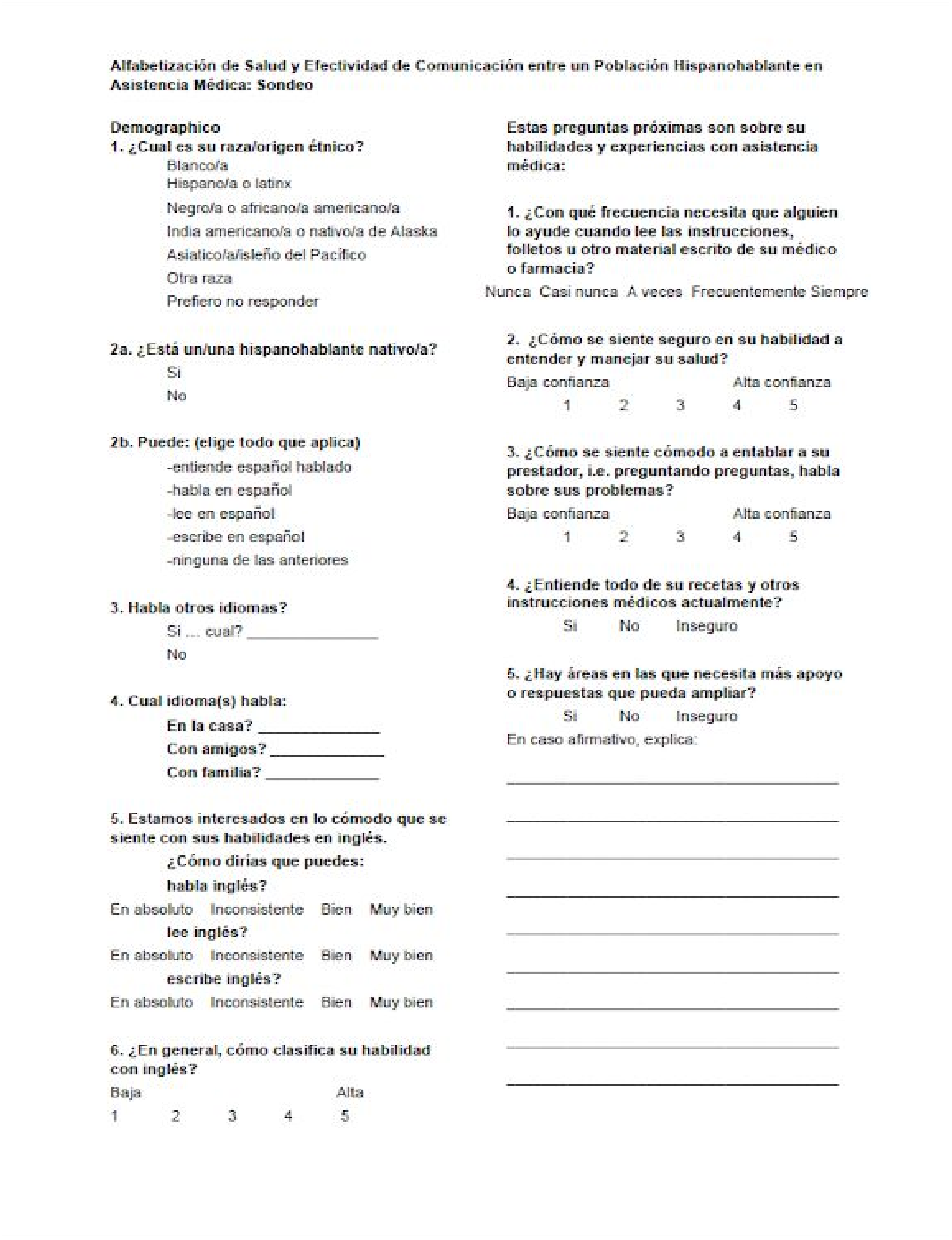
____
____
____



Alfabetización de Salud y Efectividad de Comunicación entre un Población Hispanohablante en Asistencia Médica: Sondeo

Demographico

1. ¿Cual es su raza/origen étnico?

Blanco/a
Hispano/a o latinx
Negro/a o africano/a americano/a
India americano/a o nativo/a de Alaska
Asiatico/a/isleño del Pacífico
Otra raza
Prefiero no responder

2a. ¿Está un/una hispanohablante nativo/a?

Si
No

2b. Puede: (elige todo que aplica)

-entiende español hablado
-habla en español
-lee en español
-escribe en español
-ninguna de las anteriores

3. Habla otros idiomas?

Si … cual? _______________
No

4. Cual idioma(s) habla:

En la casa? ______________
Con amigos? _____________
Con familia? _____________

5. Estamos interesados en lo cómodo que se siente con sus habilidades en inglés.

¿Cómo dirías que puedes:

habla inglés?
En absoluto Inconsistente Bien Muy bien

lee inglés?
En absoluto Inconsistente Bien Muy bien

escribe inglés?
En absoluto Inconsistente Bien Muy bien

6. ¿En general, cómo clasifica su habilidad con inglés?

Baja Alta
1 2 3 4 5

Estas preguntas próximas son sobre su habilidades y experiencias con asistencia médica:

1. ¿Con qué frecuencia necesita que alguien lo ayude cuando lee las instrucciones, folletos u otro material escrito de su médico o farmacia?

Nunca Casi nunca A veces Frecuentemente Siempre

2. ¿Cómo se siente seguro en su habilidad a entender y manejar su salud?

Baja confianza Alta confianza
1 2 3 4 5

3. ¿Cómo se siente cómodo a entablar a su prestador, i.e. preguntando preguntas, habla sobre sus problemas?

Baja confianza Alta confianza
1 2 3 4 5

4. ¿Entiende todo de su recetas y otros instrucciones médicos actualmente?

Si No Inseguro

5. ¿Hay áreas en las que necesita más apoyo o respuestas que pueda ampliar?

Si No Inseguro

En caso afirmativo, explica:

____
____
____
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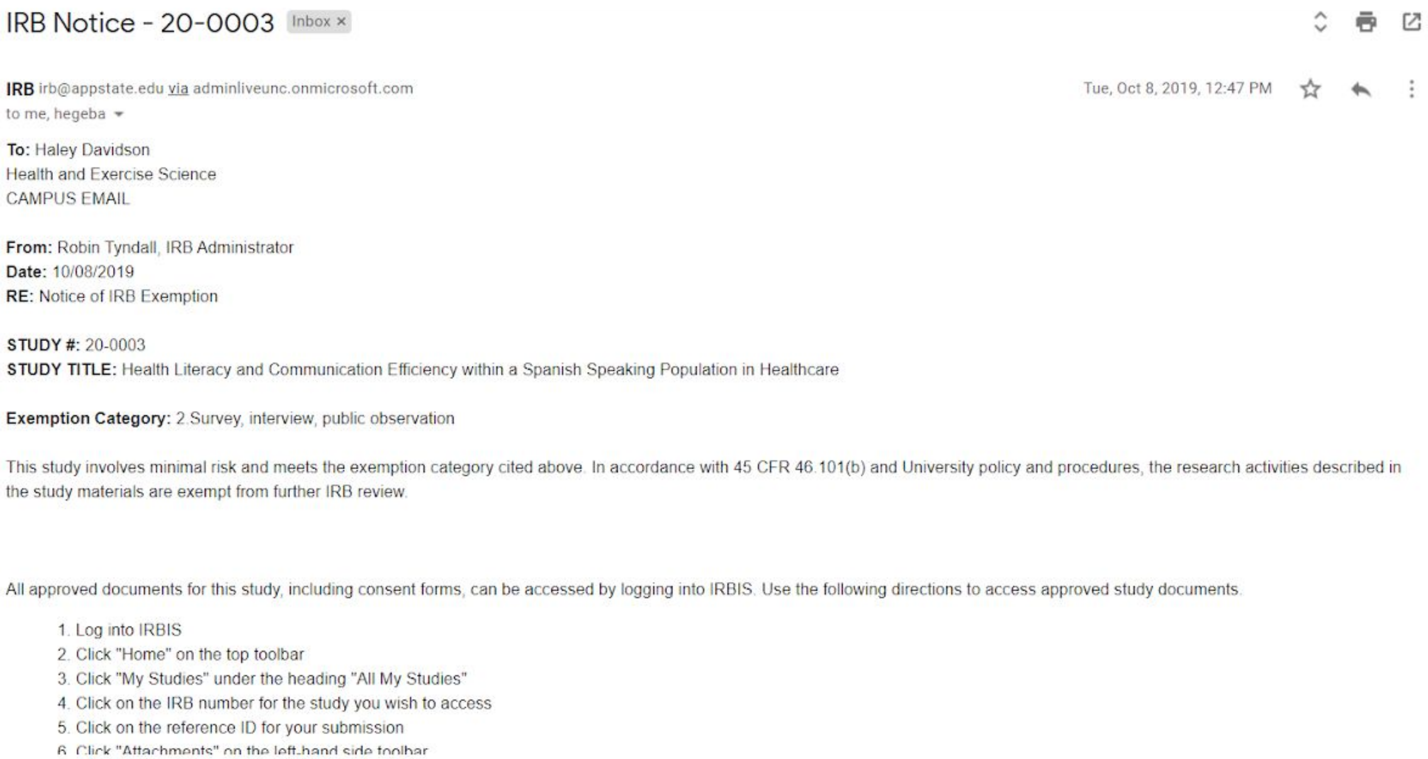
____



IRB Notice - 20-0003

IRB irb@appstate.edu via adminliveunc.onmicrosoft.com
to me, hegeba

Tue, Oct 8, 2019, 12:47 PM

To: Haley Davidson
Health and Exercise Science
CAMPUS EMAIL

From: Robin Tyndall, IRB Administrator
Date: 10/08/2019
RE: Notice of IRB Exemption

STUDY #: 20-0003
STUDY TITLE: Health Literacy and Communication Efficiency within a Spanish Speaking Population in Healthcare

Exemption Category: 2.Survey, interview, public observation

This study involves minimal risk and meets the exemption category cited above. In accordance with 45 CFR 46.101(b) and University policy and procedures, the research activities described in the study materials are exempt from further IRB review.

All approved documents for this study, including consent forms, can be accessed by logging into IRBIS. Use the following directions to access approved study documents.

1. Log into IRBIS
2. Click "Home" on the top toolbar
3. Click "My Studies" under the heading "All My Studies"
4. Click on the IRB number for the study you wish to access
5. Click on the reference ID for your submission
6. Click "Attachments" on the left-hand side toolbar