Assessment of Online Resources for Genetic Counseling and Genetic Testing

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Abstract

There is evidence that states that low genetic literacy directly affects an individual's ability to find, understand, and use genetic health information. Lack of understating of genetic information has been shown to directly lead to negative health outcomes such as decreased quality of care, increased levels of stress and anxiety, and decreased likelihood to undergo genetic testing or receive other genetic services. The aim of this study was to assess the readability and suitability of multiple online resources individuals might encounter after being referred to genetic counseling, as well as to construct an implementation guide for graphics and interactive components, which provides key insights into ways in which organizations can better frame their genetic information making it more suitable to their target audience. Researchers used the Suitability Assessment of Materials (SAM) Tool to quantify the effectiveness of various pieces of genetic literature at reaching their target audiences. Of the 20 websites that were selected, 15 received an adequate rating, while only 5 received a superior rating. The implication guide focused on areas where websites tended to receive the worst scores (graphics, learning stimulation and motivation, cultural appropriateness.) This study is significant to public health by attempting to improve organizational health literacy, and therefore improve patient and family experience.

Table of Contents

List of Tables

List of Figures

1.0 Introduction

Health literacy is "the ability of individuals to obtain and translate knowledge and information in order to maintain and improve health" (Liu et al., 2020). Despite most health-related information being written at over a tenth grade reading level, the average United States adult reads at an eighth grade reading level or below (Eltorai et al., 2018). The American Medical Association (AMA) and the National Institutes of Health (NIH) have put recommendations in place to set standards for the reading levels of health information. Both organizations recommend that the reading level of health information should be kept to below a sixth grade reading level to meet the needs of the general public. Currently however, most online health information fails to attain this goal (Hutchinson et al., 2016 & Miles et al., 2019).

Individuals who participate in genetic counseling services are often referred to the same websites, which are full of information that can be difficult to comprehend. The field of genetics has been getting significantly more attention over recent years, and new knowledge in the field continues to emerge at a rapid rate. This new knowledge can have significant impacts not only on healthcare policy and society, but also on the well-being of individuals who may be affected by genetic conditions (Bowling, 2008).

Expansion in the field of genetics is occurring so rapidly that it has been predicted that genetic testing will soon be as common as blood count tests (Green et al., 2020). Due to the recent expansion in knowledge within the field as well as the availability of genetic testing at lower costs than ever before, it has become increasingly imperative that the public has access to genetic resources. Multiple studies have been published over recent years examining the reading levels of educational materials designed for patients. Although the average reading level within the United

States population is approximately eighth grade, it has been found that patient education materials have been written at a reading level as high as twelfth grade (Eltorai, 2015). Strides have been taken over recent years to correct this public health issue, such as a greater responsibility being placed on organizations to provide information at a more feasible reading level; however, the vast number of resources available are still written at levels which are difficult for the public to understand (Kindig et al., 2004).

Often times, the gap between patients' reading levels and the reading level of health information is so large it can lead to confusion and misunderstanding of important concepts. Misinterpretation of health information, including genetic information, can have lasting effects on an individual's quality of life and could lead to life-years lost if proper actions are not being taken (Little & Gunter, 2022). For misconceptions about risk and disease progression to be prevented, the public needs to have access to relevant and reviewed information at a reading level and suitability level that is relevant to them. In order to better understand how suitable commonly used genetic websites are for the general public, this study investigated the readability and suitability of genetic education websites by using the Simple Measure of Gobbledygook (SMOG) scores and Flesch-Kincaid (FK) scores, as well as Suitability Assessment of Materials (SAM) scores of a variety of different online sources.

1.1 Specific Aims

- Conduct a suitability assessment of materials (SAM) analysis on a variety of websites in order to determine the suitability of genetic materials in diverse populations and settings.

- Determine if any area on the SAM tool is scoring poorly at higher rates than others, and address reasons why this may be occurring.

- Use the data collected through the SAM tool to make a framework which can be used as a guide in creating websites in the future with an emphasis on health literacy.

All the information gathered from this study will be used to create a framework to guide the presentation of future genetic resources to patients as well as those with limited knowledge in the field of genetics.

2.0 Background/Literature Review

2.1 Health Literacy

It is difficult to define health literacy, as it represents a broad range of concepts. Health literacy is "the ability of individuals to obtain and translate knowledge and information in order to maintain and improve health" (Liu et al., 2020). Updated definitions of this term highlight the interdependence between individuals, healthcare providers, and healthcare systems (Liu et al., 2020). Healthy People 2030 defines health literacy as having two components: personal and organizational. Personal health literacy is "the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others" (US Department of Health, 2019). Organizational health literacy is defined as "the degree to which organizations equitably enable individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others" (US Department of Health, 2019). The CDC has adapted its definition of health literacy in recent years to acknowledge that organizations have a responsibility to address health literacy, to put an emphasis on the ability of the patient to make well-informed decisions, and to support ease of access in not only using but as well as in finding health care materials (Center for Disease Control and Prevention, 2023).

Studies have been conducted to examine the readability of online health information in the past, however most of these studies focus on specific health conditions, rather than general health or the field of genetics as a whole. In a study examining the effectiveness of a list of 42 websites to communicate information about strokes to the public, it was found that only 1 website was

deemed "superior," 25 were deemed "adequate," and 16 were deemed "not suitable." This study took the average score of each subcategory on the SAM tool and found that most websites scored most poorly in the graphics section (Lee et al., 2018).

2.2 Genetic Literacy

With rapid advancements being made in the field of genetics, comes a rapid need to address genetic literacy. Similar to the definition of health literacy, genetic literacy is more than one's ability to understand genetic information as it is presented to them. A full definition describes genetic literacy as possessing sufficient knowledge of genetic principles such that individuals can make informed decisions which effect personal well-being as well as to make informed decisions on social genetic issues (Bowling et al., 2008). Many studies have been conducted in recent years that examine the health literacy of online materials. A study conducted by Guan et al. examined the content, readability, and comprehensibility of a specific form of diabetes using the SAM tool. Their study determined that most online resources pertaining to monogenic diabetes were written at a level above the comprehension level of their targeted audience (Guan et al., 2018).

Genetic literacy is a relatively new term that does not yet have a formal definition by the CDC, but it is important to recognize that for one to possess sufficient genetic literacy, appropriate genetic information needs to be made available to the public so that individuals have the ability to learn about the field independently as a means of exploring genetic conditions, concepts, tests, and treatments. To this point in time, online genetic material has often been written at a level far above the comprehension level of the general public, and this was largely because the field of genetics was more focused on research than it was on clinical applications (Abrams, et al., 2015). Now that

advancements have been made, and are continuing to be made, it is imperative that researchers, providers, and healthcare organizations keep the general population in mind when creating genetic material that can be accessed by the public (Little & Gunter, 2021).

2.2.1 Genetic Literacy Levels Found in Literature

The field of genetics has seen an increase in attention from both professionals and the public in recent years and thus there has been a corresponding increase in the importance of genetic literacy. Various studies have attempted to ascertain information relating the genetic literacy of the population, with mixed results. In a study published through the National Library of Medicine, a moderate genetic knowledge was observed, as on average half of the answers to a series of knowledge questions were correctly chosen by participants. Along with surprisingly high scores on the genetic literacy assessment, this study also noted a correlation between confidence in genetic literacy and exposure to media. Despite scores on the genetic literacy assessment, individuals who were more involved in the media, whether being from social media or news stations, possessed a greater confidence in their genetic knowledge compared to those with less exposure to media (Abrams et al., 2015).

Genetic literacy and familiarity vary quite significantly between populations. In a study including 22 countries and over 36,000 participants, familiarity of the field of genetics was very different. Among all study participants, only 35.8% reported that they were at least somewhat familiar with genetic concepts. Of the individuals pooled from India and Japan, less than 10% reported any familiarity of genetic concepts and of the individuals polled from the Italy and the United States, over 40% expressed familiarity in genetic concepts. The difference in percentages between countries can be in part accounted for by access to genetic testing and treatment options,

as well as the availability of genetic information being taught at schools and universities (Middleton et al., 2020).

In another study examining the current use and awareness of genetic testing among the United States population, it was found that 57% of participants were familiar with genetic tests and concepts. Of the individuals who expressed familiarity with the field, few were familiar with many of the purposes of genetic testing. Out of the individuals who expressed familiarity with genetic testing, less than half expressed awareness of genetic testing's role in determining treatment or drug efficiency. Over 80% of those familiar with genetic testing understood personal disease risk as well as inherited disease risk in children (Krakow et al., 2018).

There is substantial variability among genetic literacy levels between studies, and genetic literacy and awareness need to continue to be elevated as genetic testing is becoming more mainstream in today's society. Education campaigns as well as increased discussion in the healthcare setting could prove to be very beneficial in providing sufficient care to individuals across all populations.

2.2.2 Consequences of Low Health and Genetic Literacy

With the average age in the United States increasing each year, comes an increased percentage of the United States population affected by chronic diseases that require self-care as well as self-management of symptoms. The ability to find, interpret, and incorporate information on how to properly manage these conditions is becoming increasingly important. Patients with low health literacy, have higher morbidity, hospitalizations, and mortality. (Hickey et al., 2018). These negative health outcomes can be the result of a variety of different difficulties that arise due to inadequate health literacy. Patients may have difficulties setting up appointments with providers,

following directions to the office, or registering for insurance. Patients may have a hard time understanding and retaining important health information dictated to them by their providers, they may have difficulties filling out required forms to receiving treatment, as well as forms pertaining to return of results and patient consent to testing. All these obstacles compound in the mind of many individuals, discouraging them from returning to the office for follow-up appointments in the future (Safeer & Keenan, 2005).

Individuals who experience inadequate health literacy are not only affected while they are physically at a medical office, but the effects of poor health literacy are also present in many aspects of their life (Safeer & Keenan, 2005). Many individuals with poor health literacy fail to properly take their medications at the right time as well as at the right quantity, nor are they as likely as those with adequate health literacy to participate in preventative care such as cancer screening and genetic testing. Overall, these consequences that arise from low health literacy are estimated to cost over 106 to 238 billion health care dollars each year (Vernon et al., 2007).

Patients can be affected by the consequences associated with low genetic literacy in a variety of ways. It can lead to decreased quality of care, as providers may have a difficult time relaying genetic information to their patients. Misunderstanding of diagnoses as well as genetic information can also lead to increased levels of stress and anxiety in the patient and members of their family (Saulsberry & Terry, 2013). It is essential that providers have a sound understanding of genetics, as consequences of low genetic literacy in providers may include misdiagnosis, treatment failure, unnecessary genetic testing, and further complicate implementation of precision health medicine into the care plan of the patient (Swandayani et al., 2021). Studies show that individuals who score lower on genetic literacy assessments are less likely to view genetic information, and family history of disease, as a useful tool in making decisions for their own health.

Compared to individuals who scored higher on these assessments, those who scored low demonstrated decreased understanding of the implications of genetic testing and negative attitudes associated with the usefulness of genetic testing (Hooker et al., 2014).

It is becoming clearer over recent years that there is a strong connection between poor health outcomes and low health and genetic literacy. It has been found that as many as 76.7% of patients in the hospital possess inadequate health literacy levels, which has been correlated with adverse clinical events, poorer use of healthcare services, and negative health outcomes (Ruben et al., 2018). Similar studies examining the same correlation have found information quite different than Ruben and colleagues. In a study examining transitional care needs (TCNs), it was found that individuals with inadequate health literacy were significantly more likely to require additional care compared to individuals with adequate levels of health literacy. Individuals who scored poorly in the health literacy assessment were more likely to require nurse assistance with transportation, medication management, communication, along with seven other domains compared to those who scored well on the health literacy assessment. This study strengthens the existing data that inadequate health literacy has negative effects on health and health outcomes, however, this study only demonstrated a prevalence rate of 29% of patients exhibiting inadequate health literacy levels (Boyle et al., 2017). Although the above studies both show decreased health outcomes associated with low levels of health literacy, they also show a wide range of prevalence of inadequate health literacy. In addition to failing to properly manage their symptoms, individuals with low health literacy cumulatively cost the United States economy between $106 to $238 billion annually (Vernon et al., 2007). These high healthcare costs only add to the existing struggles experiences by this population, as paying off healthcare bills makes it more difficult to improve socioeconomic

status as well as to achieve higher education, which are both proven to be protective factors of health literacy levels (Hickey et al., 2018).

2.3 Interaction Between Disparities and Social Determinants with Health Literacy

The same groups have been affected by inadequate health literacy over time. The most common risk factors associated with poor health literacy are individuals with chronic diseases, those for whom English is not their primary language, older individuals, as well as those with limited education and limited income. Minoritized populations including Black and Hispanic populations score lower in assessments of health literacy compared to White populations (Hickey et al., 2017). In addition to these common risk factors affecting health literacy levels, many social determinants have an effect as well. Factors such as access to education and access to quality education also influence the health literacy of an individual (Pelikan et al., 2018). In addition to factors that influence health literacy, the office of disease prevention and health promotion (ODPHP) categorizes health literacy as a social determinant of health, as it has a direct impact on quality of health care, and therefore, health outcomes (Health Literacy, OASH). Regardless of where the true definition of health literacy falls, the association between low health literacy and poor health outcomes persists.

2.3.1 Disparities in Access to Genetic Services

Increasing amounts of genetic research shows that genetic testing can have profound effects on health outcomes in individuals with certain conditions. Despite this knowledge, and the

increased prevalence on universal screening, racial and ethnically diverse groups are still undergoing genetic testing at rates significantly less than non-marginalized groups (Muller et al., 2018). The decrease in uptake of genetic services among these groups can be explained in-part by lack of awareness, lack of trust, as well as low referral rates to genetic services. The utility of genetic testing results is also lower for minority groups, as substantially less evidence has been obtained that pertains to these groups, such as genetic variants that are more common in ethnically diverse groups (Saulsberry & Terry, 2013).

Because it is difficult to quantify a subjective variable such as community distrust, interventions such as community based participatory research and concept mapping can be used to obtain a better understanding of this issue and expedite the process towards increasing levels of trust (Christopher et al., 2008). In addition to lack of trust, low referral rates to genetic services can also be seen in minority groups. One study illustrating this examined the referral rates of patients to hereditary colorectal cancer risk screening, and significant differences were found between races. This retrospective study examined referrals to genetic evaluation as well as rates of genetic testing, and it was shown that non-Hispanic white individuals were significantly more likely to obtain referrals to genetic evaluation as well as to undergo genetic testing than Hispanic and black individuals, despite similar rates of colorectal tumor analysis (Muller et al., 2018).

2.4 Genetics in Healthcare

Over recent years, the field of genetics has become more integrated within the general population. This idea has begun to evolve with the emergence of various applications which are now becoming mainstream practices in the healthcare routines of many (Ascencio-Carbajal et al.,

2021). There are various reasons for which genetic testing could be conducted, ranging from diagnostic care to preventative care. Now that we are seeing genetics becoming far more common in clinical settings, it is important that there be a clear understanding among patients, as well as among providers, of the goals of each test.

When considering the role of genetics in healthcare, one must note the implications that genetic testing has not only on the patient, but on the family as well. It is known that many conditions have a hereditary component, meaning that gene mutations associated with a condition are commonly passed from one generation to the next. Information received by patients, as well as decisions that are made, have implications on family members. This raises many ethical concerns regarding return of results, obligation to inform, and patient confidentiality (Ascencio-Carbajal et al., 2021).

2.4.1 Genetic Testing

Due to the countless benefits, both monetary and on quality of life, it is important that patients and providers develop a sound understanding of the uses of genetic testing as well as when one should undergo genetic testing. There is a significant amount of research that demonstrates the effectiveness of genetic testing in improving health outcomes and quality of life in those affected by genetic conditions (Ascencio-Carbajal et al., 2021). Inadequate health literacy as well as disparities in access to care both lead to increased need for care, worsened health outcomes, and often a decreased quality of life. These consequences can be avoided with proper public health initiatives to ensure that individuals from all populations are receiving the same level of care (Bowling et al., 2008).

2.4.2 Role of Genetic Counselors

The genetic counseling profession is relatively new, but it has been shown to be of great benefit to individuals as they navigate their way through the difficult world of genetics. Genetic counselors are responsible for providing individuals with the knowledge necessary to make informed decisions about their genetic health as well as how to make decisions that may have effects on their families (Aliouche, 2022). Genetic counselors, in addition to their genetic training, are also trained in counseling, meaning they are there to provide psychological support to patients during times which are often quite difficult. In addition to their education and counseling, genetic counselors are also effective in communicating risk assessments, and interpretation of genetic results and literature to their patients (Skirton et al., 2015).

Genetic counselors have a role as part of the patient healthcare team at all stages of their decision-making process, even before the patient undergoes genetic testing. The genetic counselor will communicate risk and provide information empowering individuals to make an informed decision when it comes to electing for genetic testing. The genetic counselor will then be there to interpret results, provide counseling, discuss possible implications that results could have on members of their family, as well as to answer any questions the patient might have. The importance of genetic counseling has become more apparent as more individuals are electing for their services, however not all patients that undergo genetic testing get to see a genetic counselor (Aliouche, 2022). Often cost prevents patients from seeking these services, as does poor insurance coverage, lack of time and means of transportation, and at times, lack of knowledge. All these factors detour individuals from seeking out genetic counselors, at which point they turn to online resources in an attempt to obtain the same information they would have gathered from a genetic counseling consultation. While much of the information that could be found online provides useful knowledge

of genetic testing and genetic services, the information often is not as suitable as it would be coming from a licensed genetic counselor who specializes in conveying such information in a thoughtful, accessible manner. The training that genetic counselors undergo allows them to effectively discuss genetic testing services and genetic information more effectively than various online sources which tend to communicate at a level beyond the comprehension level of the public, and therefore lead to confusion and misinformation. (Skirton et al., 2015).

There have been many studies that examined the efficacy of genetic testing in terms of improving quality of life and patient outcomes (Andrews et al., 2022 & Green et al., 2020). Much of the genetic health information that is available to the public is not being used to its fullest potential. This discrepancy is accounted for by a variety of reasons, including organizations failure to present information in a way that is accessible to its targeted audience, as well as individuals' inabilities to locate, understand, and use genetic health information that is available to them (Abrams et al., 2015). This study examines virtual genetic health information that is available to the public and likely to be at the top of search results when seeking information about genetic counseling and genetic testing. The websites' suitability to their targeted audiences is scored by using the Suitability Assessment of Materials (SAM) Tool.

3.0 Data and Methods

3.1 Generating Websites

Another student researcher (MC) constructed a list of 20 websites by inputting 5 questions that patients may have after being referred to genetic testing prior to their genetic counseling appointment into a Google search. This system of generating websites is similar to those conducted in similar studies (Rhee et al., 2013). Each question was entered in an incognito browser, as a means of eliminating search history bias, and searched on google.com. Due to the changing nature of webpage rankings on google.com, all web pages were collected on the same day, March 22, 2022. A list of the questions can be seen below:

1. What is a genetic counselor?
2. What is genetic testing?
3. Why do I need genetic testing?
4. What happens at a genetic counseling appointment?

Upon obtaining a list of 20 websites, MC placed each website into a category according to the original source of the website. A number of websites resulted in the top 5 websites on multiple occasions as a result of differing searches on google.com. Duplicate websites were included in this analysis as to provide an increased weight to websites that would likely be seen by more individuals. Each of the websites that were analyzed came from either governmental, educational, nonprofit, or healthcare agencies, which is outlined in the table below.

Table 1. List of Websites by Source

Government	Healthcare	Nonprofit	Professional
MedlinePlus	Cincinnati Children's Hospital	Breastcancer.org	American Society of Clinical Oncology
CDC	Mayo Clinic		American Academy of Family Physicians
National Human Genome Research Institute	Nemours KidsHealth		American College of Medical Genetics
			National Society of Genetic Counselors

3.2 Assessing Readability

Flesch-Kincaid (FK) and the simple measure of gobbledygook (SMOG) scores are effective means of assessing the reading level of health-related resources. Both readability tools take sentence length, number of sentences, and number of syllables into consideration in determining the readability of each resource (Eltorai et al., 2014). The readability scores obtained from both measures can be used to calculate the text readability grade level for each resource being scored.

Both FK and SMOG scores were used to assess the readability of each website. FK scores were used to analyze the average number of syllables per word as well as the number of words in each sentence. SMOG scores were used to examine the number of multiple syllable words per sentence. MC gathered each of these scores by copying each webpage and inputting it into a readability generator online.

3.3 Assessing Suitability

The suitability of a website is equally as important to the reading level of a website, as it assesses the ability to communicate information to a targeted audience. The author (AM) and MC used the suitability assessment of materials (SAM) tool to determine the suitability of a list of the 20 websites previously generated. This tool is proficient at providing a means of quantifying the suitability of six different areas of health-related materials. The SAM tool rates readability in a variety of factors, including content, literacy demand, graphics, layout, and type, learning stimulation and motivation, and cultural appropriateness (Doak, 1996). The purpose of using the SAM tool to assess these websites is to assess the readability and comprehension levels of the information provided. Doing so will measure how the target audience will comprehend the material, give a quantitative measure to aid in the comparison of websites, and act as a guide in scoring the cultural appropriateness of materials.

Researchers generated a list of 20 websites from multiple google searches of common questions patients referred to genetic counselors may have. The findings of this study add to the expanding set of previously conducted studies showing that genetic literature must be written at a lower reading level, while at the same time providing information in a clearer way to its targeted audience (Guan et al., 2018). A breakdown of each SAM category can be seen below:

Table 2. Suitability Assessment of Materials Categories

Category Being Rated	Subcategory
Content	Purpose is evident, content about behaviors, scope is limited, summary or review included
Literacy Demand	Reading grade level, writing style, vocabulary use common words, context is given first, learning aids
Graphics	Cover graphic shows purpose, types of graphics, relevance of illustrations, lists and tables explained, captions used for graphics
Layout/Typography	Layout factors, typography, subheadings used
Learning Stimulation/Motivation	Interaction used, behaviors are modeled and specific, motivation, self-efficacy
Cultural Appropriateness	Match in logic, language, and experience (LLE), cultural image and examples

1. Table was adapted from the Suitability Assessment of Materials form shown in Appendix A

Each subcategory was then given a score of 2 (superior), 1 (adequate), 0 (not suitable), or N/A (not applicable). The final score of the website was calculated by dividing the total score for the website by the maximum number of points that website could receive. The maximum number of points was calculated by multiplying the number of subcategories scored as N/A by 2 and subtracting that from the maximum possible score (44). The percent score was calculated by dividing the total score by the adjusted maximum score. The final suitability of the website could be scored as superior (>70%), adequate (40%-70%), or not suitable (<40%).

Each reviewer scored all the subcategories and shared their findings with each other. Major discrepancies were handled in a 1 on 1 meeting to ensure both parties had the same interpretation of category descriptions. Subsequent discrepancies were brought to a third party (EF) who then

scored the websites independently prior to reviewing the initial reviews. On these occasions, an average score was taken among each of the three scorers, which was used to determine the SAM rating for the website.

4.0 Results

Tables 3-6 show the average website score between each of the scorers, as well as the overall website rating. Once an average SAM score was taken among each of the scorers, no websites were deemed to be "not suitable" (score range 0.0 - 0.39). The average SAM scores among each of the readers shows that 15 of the webpages were of adequate rating (score range 0.40 – 0.69), while 5 webpages were of a superior rating (score range 0.70 – 1.00). A link to each of the following websites are located in Appendix B.

Table 3. Website Scores for "What Is a Genetic Counselor?"

Website Title (Sponsor)	Average SAM Score	Website Rating	Website URL
Genetic Counseling (CDC)	0.6065	Adequate	https://www.cdc.gov/genomics/gtesting/genetic_counseling.htm
Genetic Counseling Graduate Program (Cincinnati Children's Hospital)	0.6542	Adequate	https://www.cincinnatichildrens.org/education/clinical/student-grad/genetic-counseling/prospective-students
About Genetic Counselors (National Society of Genetic Counselors)	0.4625	Adequate	https://www.nsgc.org/About/About-Genetic-Counselors
Genetic Counseling (National Human Genome Research Institute)	0.5804	Adequate	https://www.genome.gov/genetics-glossary/Genetic-Counseling
What To Expect When Meeting with A Genetic Counselor (American Society of Clinical Oncology)	0.7292	Superior	https://www.cancer.net/navigating-cancer-care/cancer-basics/genetics/what-expect-when-meeting-genetic-counselor

Table 4. Website Scores for "What Is Genetic Testing?"

Website Title (Sponsor)	Average SAM Score	Website Rating	Website URL
What is Genetic Testing (MedlinePlus)	0.5490	Adequate	https://medlineplus.gov/genetics/understanding/testing/genetictesting/
Genetic Testing (CDC)	0.7458	Superior	https://www.cdc.gov/genomics/gtesting/genetic_testing.htm
Genetic Testing (Mayo Clinic)	0.5667	Adequate	https://www.mayoclinic.org/tests-procedures/genetic-testing/about/pac-20384827
Genetic Testing (National Human Genome Research Institute)	0.5533	Adequate	https://www.genome.gov/genetics-glossary/Genetic-Testing
Genetic Testing (Nemours KidsHealth)	0.7363	Superior	https://kidshealth.org/en/parents/genetics.html

Table 5. Website Scores for "Why Do I Need Genetic Testing?"

Website Title (Sponsor)	Average SAM Score	Website Rating	Website URL
Genetic Testing (CDC)	0.7458	Superior	https://www.cdc.gov/genomics/gtesting/genetic_testing.htm
What are the Benefits of Genetic Testing (Medline Plus)	0.5135	Adequate	https://medlineplus.gov/genetics/understanding/testing/benefits/
Genetic Testing (Mayo Clinic)	0.5667	Adequate	https://www.mayoclinic.org/tests-procedures/genetic-testing/about/pac-20384827
Making Smart Decisions About Genetic Testing (American College of Medical Genetics)	0.6881	Adequate	https://www.choosingwisely.org/patient-resources/making-smart-decisions-about-genetic-testing/
Genetic Testing: What You Should Know (American Academy of Family Physicians)	0.6250	Adequate	https://familydoctor.org/genetic-testing-what-you-should-know/

Table 6. Website Scores for "What Happens at a Genetic Counseling Appointment?"

Website Title (Sponsor)	Average SAM Score	Website Rating	Website URL
What to Expect When Meeting with a Genetic Counselor (American Society of Clinical Oncology)	0.7292	Superior	https://www.cancer.net/navigating-cancer-care/cancer-basics/genetics/what-expect-when-meeting-genetic-counselor
What Happens During a Genetic Consultation (Medline Plus)	0.5375	Adequate	https://medlineplus.gov/genetics/understanding/consult/expectations/
Genetic Counseling- For Parents (Nemours KidsHealth)	0.6583	Adequate	https://kidshealth.org/en/parents/genetic-counseling.html
How to Prepare for Genetic Counseling (Breastcancer.org)	0.6222	Adequate	https://www.breastcancer.org/genetic-testing/what-to-expect
Frequently Asked Questions About Genetic Counseling and Testing (University of Iowa Hospitals and Clinics)	0.6194	Adequate	https://uihc.org/health-topics/frequently-asked-questions-about-genetic-counseling-and-testing

A third scorer (EF) was utilized to settle discrepancies on 3 occasions. The following websites were scored by averaging the SAM score of 3 scorers, while the other 17 websites were scored by average the SAM scores given by the two primary scorers:

1. What are the benefits of genetic testing (MedLine Plus)

2. Making smart decisions about genetic testing (American College of Medical Genetics)

3. Genetic testing: What you should know (American Academy of Family Physicians)

The average success rate of each category of the SAM tool was determined by dividing the average score per website by the maximum score of each website. The average score for each of the six categories of the SAM tool can be found in table 1. A crude success rate as well as an adjusted success rate is included where applicable in order to obtain a clearer estimate of the

success of each website in each category. The adjusted scores took into consideration SAM subcategories that were not present in a specific website. A total success rate was calculated for each website, as well as an adjusted success rate, which instead of counting "N/A" results as a 0, and therefore decreasing the success rate, the "N/A" results were adjusted in a way which did not decrease nor increase the success rate of a particular subcategory.

Table 7. Overall SAM Statistics

Factor Being Rated	Max Score per Website (Adjusted Max Score)	Average Score per Website	Success Rate (Adjusted Rate)
Content	8	5.1	63.75%
Literacy Demand	10	6.55	65.5%
Graphics	10 (3.4)	1.25	12.5% (36.76%)
Layout and Typography	6 (5.95)	3.95	65.83% (66.39%)
Learning Stimulation, Motivation	6	3.4	56.67%
Cultural Appropriateness	4 (3.4)	1.6	40% (47.06%)

Each researcher independently scored each website using the SAM tool, and while results were often similar, there were some discrepancies to work through. One reader scored six of the websites as superior compared to the other reader who only scored three as superior in suitability.

One reader scored 14 websites as adequate, while the other scored 16 as adequate. One reader did not score any website as not suitable while the other reader scored one as not suitable. A breakdown of the scores given by each of the readers is depicted in Figure 1.

Figure 1. SAM Score Comparison

SAM SCORE COMPARISON BETWEEN SCORERS
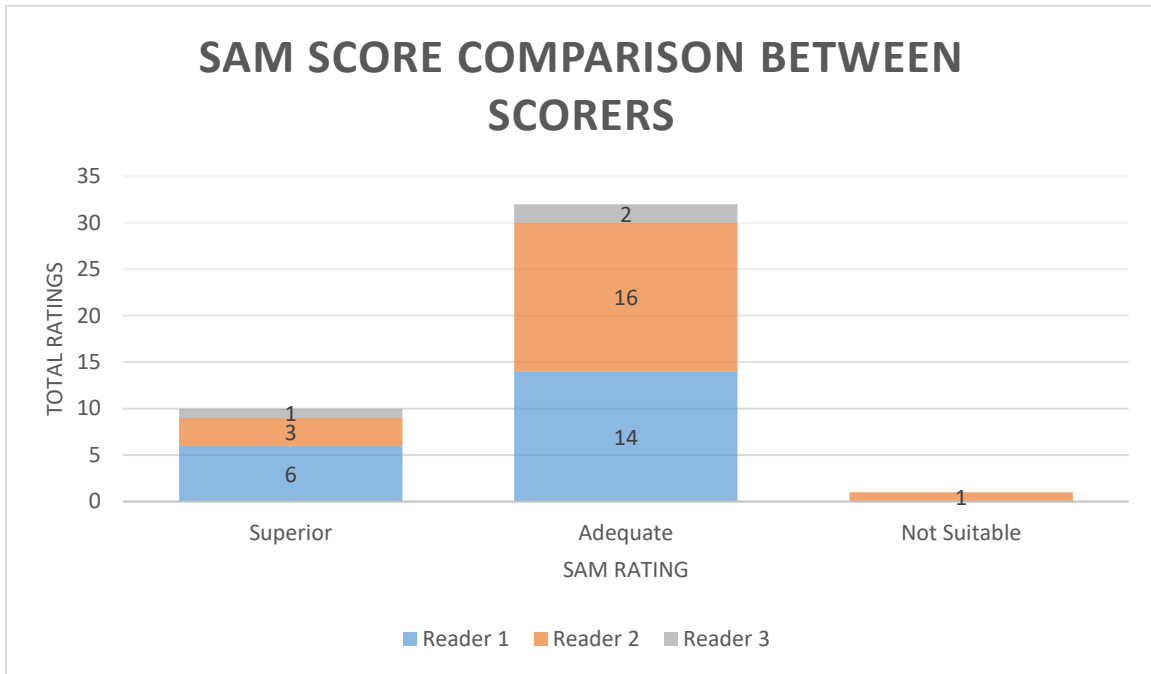
Of the 20 websites, 8 were created by a government organization, 7 were created by a healthcare organization, 4 were created by a professional organization and 1 was created by a nonprofit organization. The website rating varied slightly among different types of organizations. Out of the 8 government organizations, 2 (25%) received a superior rating, 6 (75%) received an adequate rating, and no websites (0%) were rated as not suitable. Out of the 7 healthcare organizations, 2 (28.57%) received a superior rating, 5 (71.43%) received an adequate rating, and no websites (0%) were rated as not suitable. Out of the 4 professional organizations, 1 (25%) received a superior rating, 3 (75%) received an adequate rating, and no websites (0%) were rated

as not suitable. The only nonprofit organization represented in this study received an adequate rating.

Figure 2. Combined Suitability Results
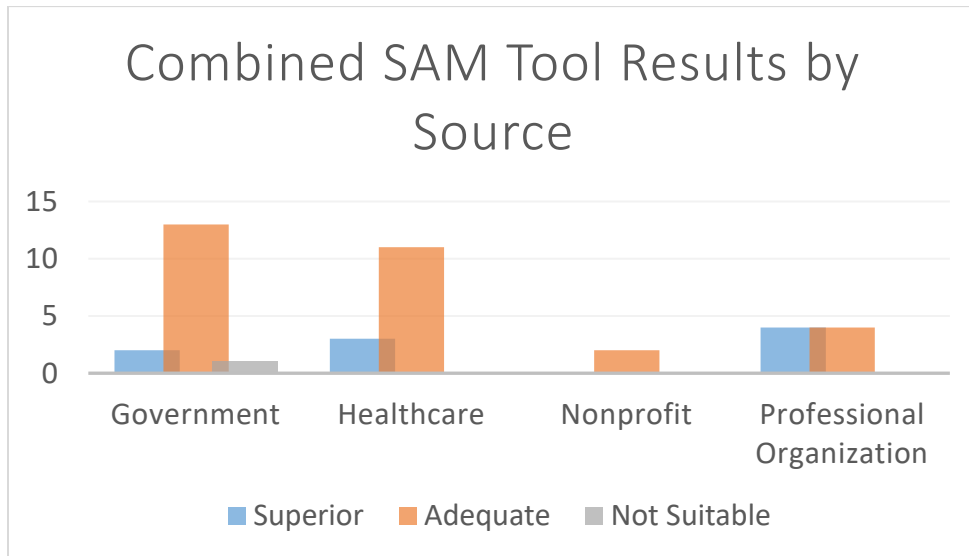
To determine how much variability in SAM score could be explained by the reading level of each website, the researcher found a coefficient of determination (R-Squared). The R-squared value explaining this correlation is 0.3405. This value signifies that that reading level and SAM score are moderately correlated, as 34.05% of the variability in SAM score can be accounted for by the reading level. Figure 3 shows the scatterplot depicting this correlation. Each point in the scatterplot represents the SAM score and the reading level of each website. The decreasing slope of the trendline suggests that as reading level decreases, SAM scores increase.

Figure 3. Suitability and Readability Scatterplot

Reading Level

Suitability and Readability Scatterplot

$R^2 = 0.3405$

SAM Score
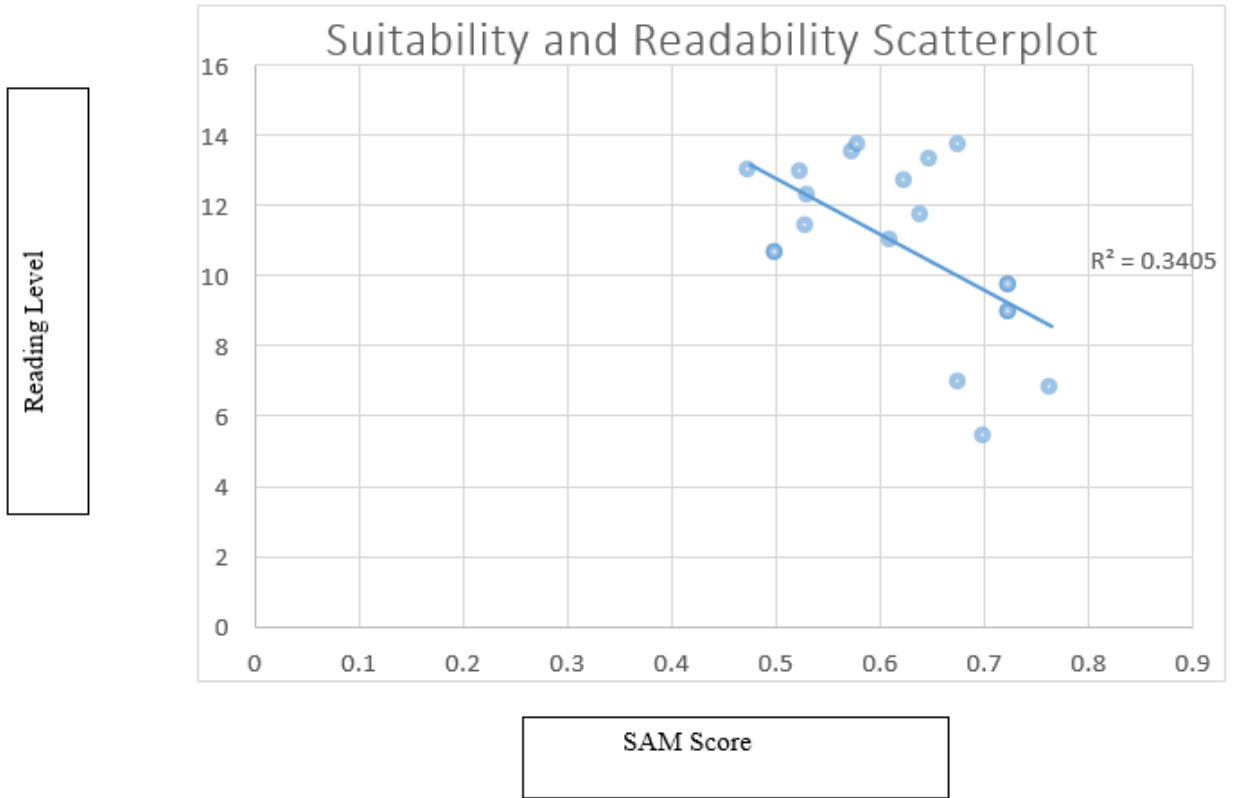
5.0 Implementation Guide

Many organizations make an effort to share useful health information with the public, however they often fail to do so in a way which is suitable to their targeted audience. Lack of familiarity with the factors included in the SAM tool, and lack of awareness of the concept of organizational health literacy could play a role in this discrepancy. Some components of a website can be amended through online resources, such as an online reading level assessment, where other components may require more attention to ensure that the message the organization is trying to convey reaches their target audience. Our study found that websites tended to score poorly on three categories of the SAM Tool compared to others.

1. Graphics
2. Learning Stimulation and Motivation
3. Cultural Appropriateness

5.1 Improving Online Literature through Using Appropriate Graphics

This study found that inclusion of appropriate graphics would be one of the most meaningful way of improving the suitability of a website. The SAM Tool breaks the graphic category down into multiple subcategories, totaling the most potential points out of any other category on the tool. The websites present in this study scored poorly in all subcategories, averaging lower than a 1 out of 2 in each subcategory. An easy means of improving scores, and

therefore readability and suitability, of a website would be to pay attention to each graphics category listed in the SAM Tool.

For a reader to feel less overwhelmed and distracted by a webpage, it is important that the website contains a cover image that is friendly and relevant to the information being given. A great example of a cover photo showing purpose can be found on the genetic testing website by the CDC (CDC, 2022). The image clearly shows that the website is related to the field of genetics, and it is not distracting or confusing. In addition to including an appropriate cover graphic, inclusion of graphics can be helpful as long as they do not distract the reader from important information, and they are related to the information being conveyed on the website. The genetic counseling website by the NHGRI does a great job at including graphics that complement the information being given on the page (National Human Genome Research Institute, 2023). This website also has an option to read the text aloud, which made it exceptionally accessible to a wide variety of populations.

Other ways of improving the quality of a website through the inclusion of graphics is to include simple and familiar illustrations. The point of adding illustrations to an online health resource is not to convey extremely complex information, but to break up the text and depict something that was previously stated on the webpage in a different way. Inclusion of lists and tables are also extremely effective ways of increasing the suitability of a website. Rather than spelling out figures and numbers within the body of a website, including well organized lists and tables is a great way to convey certain types of information. On instances where including lists and tables to a webpage is appropriate, the author must ensure that each figure is explained within the text and by a concise caption. Although none of the websites present in this study contained a list or table, effective uses of captions can be found in multiple other genetic resources such as:

- The Government Accountability Offices' Report on Genetic Services (GAO, 202)

- https://www.gao.gov/assets/gao-20-593.pdf
- The Prenatal Genetic Testing Chart published by The American College of Obstetricians and Gynecologists (ACOG, 2023)
  - https://www.acog.org/-/media/project/acog/acogorg/womens-health/files/infographics/prenatal-genetic-testing-chart.pdf?la=en&hash=34D50DE41EDC8300709BB9D92C6F71DF
- The Youngtimers Guide to Genetic Testing (Youngtimers, 2021)
  - https://www.youngtimers.org/guidetogenetictestingpart1

5.1.1 Graphic and Caption Examples

When using graphics on a website, it is important to use friendly and familiar images that the targeted audience may have already seen in the past. The intention of graphics is not to teach new, complex ideas, but to allow the audience to visually grasp key ideas.
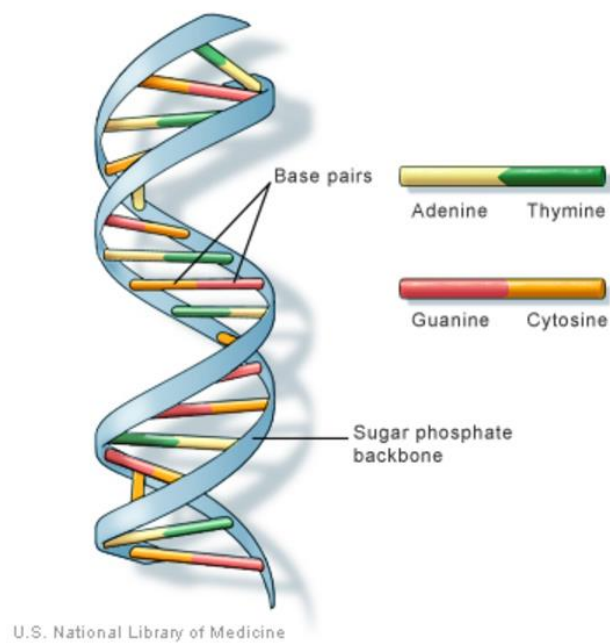
Example 1.

Figure 4. Strand of DNA

Obtained from: https://www.pharmaceutical-technology.com/features/gene-writing-future-

genetic-medicine/

Example 2.

Figure 5. Double Helix DNA Strand: Made Up of Base Pairs on a Phosphate Backbone

Obtained from: https://medlineplus.gov/genetics/understanding/basics/dna/

Example 3.

Figure 6. Genetic Counseling Illustration

Obtained from: https://thehealthcarehustlers.com/blog/2018/11/25/the-basics-genetic-counseling-and-testing

5.2 Improving Online Literature Through Learning Stimulation and Motivation

When creating genetic health material, one must do their best to hold the interest of their audience. The websites present in this study scored particularly well in most subcategories in this section including "behaviors are modeled and specific" and "self-efficacy/motivation." Authors should break down complex ideas into small sections, as to motivate the reader to continue and foster understanding of information. Websites should also include instructions for their reader, such as next steps that could be taken, or to show specific behaviors that could improve their health outcomes. The website by the American Society of Clinical Oncology titled "What to expect when meeting with a genetic counselor," did a great job of framing their webpage in a way which held the interest of the reader as well as promoted understanding and self-efficacy (American Society of Clinical Oncology, 2021). This website broke topics down into bulleted lists and short

paragraphs and provided instructions as to next steps to finding more information. It even listed ways to act, by preparing for a visit with a genetic counselor. When looking at this website, it is not an intimidating block of text, it is many small paragraphs broken up by questions and lists, which is much easier to follow than other formats of websites.

Websites tended to score quite poorly in the "interactions used" subcategory, scoring on average 0.45 out of the possible 2 points. To score well in this subcategory, authors can include questions to stimulate thinking in their audience or employ a question-and-answer format to foster thought in their audience. Almost all the websites present in this study provided information in paragraph format, with multiple subcategories. This is an effective means of communicating information, however it is not effective in maintaining the interest of the reader. Large blocks of text are often confusing, and force individuals to read them multiple times before they can better comprehend the information. An effective means of improving an individual's ability to maintain focus could be by asking and answering questions that foster thought within the body of text. Both Nemours KidsHealth and the University of Iowa did very well in this category in their websites titled Genetic Testing and Frequently asked questions about genetic counseling and testing respectfully (Nemours KidsHealth, 2021 & University of Iowa, 2016). Each time new information is presented within these websites, it is presented in the form of a question, intriguing readers through a form of passive interaction.

5.3 Improving Online Literature Through Cultural Appropriateness

When creating a website to foster health and well-being to the public, an author should attempt to reach as many populations as possible. In doing so, they must be cognizant to be

inclusive to all groups, and demonstrate that the information they are sharing is relevant to multiple populations. The SAM Tool breaks cultural appropriateness down into two categories, "match in logic, language, and experience (LLE)" and "cultural image and examples." The websites present in this study scored better in the "match in LLE" subcategory compared to the "cultural image and examples" subcategory.

When creating a website that will be seen by a variety of populations and cultures, the author must ensure that the central concepts and ideas appear in a way that is culturally like the LLE of other populations. This can be achieved by avoiding complex terminology, or expressions that may not be received by all populations. An easy way of increasing the suitability of websites in this category would be to include culturally appropriate images. Authors can include images of individuals from a variety of populations, to show that the information being given is not only directed at one population, but to a variety of cultures and populations. The "Genetic counseling graduate program" website from the Cincinnati Children's Hospital did a great job of demonstrating their cultural competency by including inclusive language as well as representing multiple populations in a video they included about their organization (Cincinnati Children's Hospital, 2022).

5.4 Example of Genetic Testing/Counseling Information

GENETIC TESTING

Magnified DNA Strand

What is Genetic Testing?

Genetic testing is a type of medical test. This type of test is used to look for changes in genes, chromosomes, and proteins. These changes can cause genetic illnesses. Genetic testing is used to find gene changes that could affect an individual, or that they can pass down to their children.

What Can Genetic Testing Find?

A positive genetic test does not mean you will definitely develop a condition. This type of testis used to confirm or rule out conditions such as:

- Down Syndrome
- Huntington's Disease
- Cystic Fibrosis
- Certain types of Cancer

Genetic Counseling Consolation

Who Should Consider Genetic Testing?

There are many reasons why people use genetic testing services, such as to:

- Learn if a pregnancy is affected by a genetic illness
- Learn if a child has a genetic illness
- Learn if they are affected with a genetic illness that runs in the family
- Guide treatment plans for certain conditions

Where Can I learn More About Genetic Testing?

Genetic counseling is a great way to learn more about genetic conditions. A doctor can refer you to this service if they believe it would be helpful. Genetic counselors are trained to deliver genetic knowledge in a clear and understandable way. Genetic counselors help:

- Manage your own health
- Plan your pregnancy
- Care for a child with a genetic condition

5.4.1 Characteristics of the Sample Information

- Overall reading level of 6.97

  - Paragraph 1 reading level: 7.1

  - Paragraph 2 reading level: 6.9

  - Paragraph 3 reading level: 6.6

  - Paragraph 4 reading level: 7.3

- Short paragraphs are used to assist readers in self-motivation.

- Bulleted lists are used to allow easy access to information.

- The purpose is evident.

- The content provided is behavioral.

- Information is conveyed using the active voice.

- Context is given first.

- The graphics are simple and familiar.

- The cover graphic shows purpose.

- Information is presented in a question-and-answer format.

- There is a neutral presentation of cultural images.

6.0 Conclusion and Implications

Many of the SAM scores (n=30) were of adequate suitability, meaning that although they effectively communicate material to their targeted audience, there is significant room for improvement. This finding is consistent with results found in prior experiments examining patient health material (Guan et al., 2018) The cultural appropriateness as well as the graphics categories tended to receive the lowest scores out of each of the 20 websites. Failure to score highly in these sections is largely due to websites failing to include illustrations that were friendly and familiar to the audience, as well as failing to include illustrations all together. Websites that scored higher were much more likely to include illustrations as well as descriptions of each illustration included on the website.

Only three of the websites examined in this study were of adequate reading level. One of these sites (Genetic Testing (Nemours KidsHealth)) scored a superior rating at 0.7363, while the two other sites (Genetic Testing: What you should know & Making smart decisions about genetic testing) scored adequate ratings of 0.6250 and 0.6881 respectively. The average US adult reads between a fifth grade and an eight-grade reading level (Safeer & Keenan, 2005). The average reading level between each of the websites was 10.84 with a maximum of 13.7 and a minimum of 5.4. A weak correlation was found between the reading level and the SAM score of each website. A coefficient of determination of 0.3405 was found, meaning that about 34.05% of the variability in SAM score could be accounted for by reading level. Maintaining a low reading level likely leads to improving SAM score for multiple reasons. Reading level is a subcategory in the literacy demand section of the SAM Tool, meaning that maintaining a low reading level has a direct impact on the SAM score. In addition to being a specific subcategory within the SAM tool, maintaining

an appropriate reading level indirectly spans across multiple categories. For example, subcategories such as "vocabulary uses common words", "purpose is evident", and "summary or review included", are all impacted based off author's abilities to maintain a proper reading level in their text. While theses categories are not specifically affected by FK reading levels scores, the emphasis on clearly communicating and using common words effects the overall SAM score in multiple ways. Similarly, high reading levels of websites are directly associated with a poor SAM score. It is likely that organizations who were more cognizant of maintaining a low reading level were also more cognizant of maintaining appropriate organizational health literacy. Although individuals all read at different levels, everyone benefits from reading information written with organizational health literacy in mind. This type of information tends to be more concise and straightforward than other literature that uses confusing terminology or embellishes their literature with information that is not necessarily relevant or helpful to the reader.

Differences in suitability scoring among readers can be due to a number of factors. Ambiguity in SAM Tool scoring guidelines can lead to varying interpretations of scoring procedures. The SAM Tool also places a lot of emphasis on the presence of graphics in each resource. Failure to include an appropriate illustration effects the overall score across multiple categories including graphics, cultural appropriateness, and layout and typography. The weight given to graphics can skew results between readers as ambiguity in SAM scoring guidelines can lead to many subcategories receiving varying scores due to subjectivity of scoring guidelines.

Although, compared to the other categories of the SAM Tool, most websites scored relatively well in the content section at a 63.75% success rate, this number was heavily affected by the absence/presence of a summary at the end of the website. Most websites did not have a summary of materials, and because this was a subcategory on the SAM Tool, hurt the overall score

of many websites. Out of the 20 websites examined, only 6 of them had a summary, and only 2 had a full summary section. This finding is consistent with what has been found in previous studies examining patient health materials as well (Ryan et al., 2014).

Of the websites scored, eight were from governmental sources, seven were from healthcare sources, one was from a nonprofit organization, and four were from professional organizations. It is important to keep in mind that healthcare is a business, and organizations attempt to get their information seen by the highest number of viewers possible. This is likely due to the fact that they find a correlation between website views and sales of their product or services. That is to say that larger organizations, such as governmental organizations and hospital systems, can afford to put more money into marketing, and therefore see more traffic through their websites. The analysis of websites using the SAM tool in no way measures the credibility of the information presented in each website. The truthfulness of each webpage on the internet is always partially in question due to potential biases and conflicting interests of each organization. The presence of conflicting information, and information that can be misleading needs to be taken into consideration when using web-based materials to obtain important health information.

One reader scored 6 out of the 20 websites as superior and the other 14 websites as adequate. Of the 6 websites that were scored superior, 3 were from professional sources, 2 were from government organizations, and 1 was from a healthcare organization. Out of all the professional websites scored, 75% scored a superior rating and 25% scored an adequate rating. Out of all the governmental websites scored, 25% scored a superior rating and 75% scored an adequate rating. Out of all the healthcare websites scored, about 14% scored a superior rating and about 86% scored an adequate rating. The only nonprofit website that was scored received an adequate rating. The breakdown of suitability scores by website source further demonstrates that

the majority of webpages present health information adequately to their targeted audience. Although the targeted audience did vary among the websites, for example one website that was scored, the genetic counseling graduate program in Cincinnati, tailored their website towards prospective genetic counseling graduate students, where other websites tailored their information to a lay audience.

Overall, most of the websites scored were adequately suited to their targeted audience, rather than being ideally suited. Additionally, most websites were written with reading levels significantly higher than the average reading level of the US population. That is to say, that although many organizations are adequately reaching their targeted audience, some of the information they are trying to convey may not be appropriately resonating with their target audience. In the future, organizations should be more cognizant of reading level and suitability when creating health-related material. They can do this by using illustrations to convey complex information. They can also do so by providing lists, headings, and ensuring that sentences are not too long and full of embedded information.

6.1 Limitations

Although results from each scorer were very similar, small differences in scoring led to different SAM score results. The subjective nature of the SAM Tool leads to minor discrepancies in scoring, however the majority of differences in scores can be attributed to ambiguity in the SAM Tool guidelines. Many subcategories include vague descriptions of each subcategory, making equal scoring among readers nearly impossible. The SAM Tool also places a large emphasis on the inclusion of graphics, which affects the overall SAM score multiple times in the scoring

process. For example, failing to include a graphic has negative effects on three out of the 6 categories of the SAM Tool.

Many of the websites that were scored had a variety of goals to be conveyed to their audience. Scoring websites that have different goals in mind using the same tool did not always transfer over well. One example of this is when considering the reading level in the literacy demand section. In a website tailored to genetic counseling graduate students, it makes sense that the reading level would be higher than in a website aimed at relaying genetic information to children. This distinction caused multiple websites to receive lower scores than others, even though they had different goals as well as different target audiences as compared to other websites.

Out of the 20 websites scored, 3 of them were duplicates. Due to the nature of website inclusion, one three separate occasions, a website appeared in the top five results of a different google search twice. Therefore, results given to three websites possess twice the weight as other websites in this study. Discrepancies in SAM scores given to these websites further skew the overall discrepancies between scorers, as each result was counted twice. The effect of duplicate websites would be made smaller if this study contained a higher sample size of websites. Scoring more websites would also offer a clearer understanding of trends that exist in SAM scores between sources as well.

Appendix A Suitability Assessment of Materials Form

Suitability Assessment of Materials (SAM)

Title of teaching material:
Date: **Your name:**

FACTOR TO BE RATED   **SCORE**   **COMMENTS**

2 points for superior rating
1 point for adequate rating
0 points for not suitable rating
N/A if the factor does not apply to this material

I. CONTENT

(a) Purpose is evident   _____
2 Purpose is explicitly stated in title, or cover illustration, or introduction.
1 Purpose is not explicit. It is implied, or multiple purposes are stated.
0 No purpose is stated in the title, cover illustration, or introduction.

(b) Content about behaviors   _____
2 Thrust of the material is application of knowledge/skills aimed
   at desirable reader behavior rather than nonbehavior facts.
1 At least 40 percent of content topics focus on desirable behaviors or actions.
0 Nearly all topics are focused on nonbehavior facts.

(c) Scope is limited   _____
2 Scope is limited to essential information directly related to the purpose.
   Experience shows it can be learned in time allowed.
1 Scope is expanded beyond the purpose; no more than 40 percent is
   nonessential information. Key points can be learned in time allowed.
0 Scope is far out of proportion to the purpose and time allowed.

(d) Summary or review included   _____
2 A summary is included and retells the key messages in different words and examples.
1 Some key ideas are reviewed.
0 No summary or review is included.

2. LITERACY DEMAND

(a) Reading grade level   _____
2 5th-grade level or lower (5 years of schooling level).
1 6th-, 7th-, or 8th-grade level (6-8 years of schooling level).
0 9th-grade level and above (9 years or more of schooling level).

SAM   1

42

FACTOR TO BE RATED	SCORE	COMMENTS

(b) Writing style, active voice
2 Both factors:
    (1) Mostly conversational style and active voice.
    (2) Simple sentences are used extensively; few sentences contain embedded information.
1 (1) About 50 percent of the text uses conversational style and active voice.
    (2) Less than half the sentences have embedded information.
0 (1) Passive voice throughout.
    (2) Over half the sentences have extensive embedded information.

(c) Vocabulary uses common words
2 All three factors:
    (1) Common words are used nearly all of thetime.
    (2) Technical, concept, category, value judgment (CCVJ)words are explained by examples.
    (3) Imagery words are used as appropriate for content.
1 (1) Common words are frequently used.
    (2) Technical and CCVJ words are sometimes explained by examples.
    (3) Some jargon or math symbols are included.
0 Two or more factors:
    (1) Uncommon words are frequently used in lieu of common words.
    (2) No examples are given for technical and CCVJ words.
    (3) Extensive jargon.

(d) Context is given first
2 Consistently provides context before presenting new information.
1 Provides context before new information about 50 percent of the time.
0 Context is provided last or no context is provided.

(e) Leaming aids via "road signs," subtitles and captions
2 Nearly all topics are preceded by an advance organizer
    (a statement that tells what is coming next).
1 About 50 percent of the topics are preceded by advance organizers.
0 Few or no advance organizers are used.

3. GRAPHICS

(a) Cover graphic shows purpose
2 The cover graphic is
    (1) friendly,
    (2) attracts attention,
    (3) clearly portrays the purpose of the material to the intended audience.
1 The cover graphic has one or two of the superior criteria.
0 The cover graphic has none of the superior criteria.

SAM
2

FACTOR TO BE RATED   **SCORE**   **COMMENTS**

(b) Type of graphics
2 Both factors: (1) Simple, adult-appropriate, line drawings/sketches are used.
    (2) Illustrations are likely to be familiar to the viewers.
1 One of the superior factors is missing.
0 None of the superior factors are present.

(c) Relevance of illustrations
2 Illustrations present key messages visually so the reader/viewer can
    grasp the key ideas from the illustrations alone. No distractions.
1 (1) Illustrations include some distractions.
    (2) Insufficient use of illustrations.
0 One factor: (1) Confusing or technical illustrations (nonbehavior related).
    (2) No illustrations, or an overload of illustrations.

(d) Lists and tables explained
2 Step-by-step directions, with an example, are provided that will
    build comprehension and self-efficacy.
1 "How-to" directions are too brief for reader to understand and
    use the graphic without additional counseling.
0 Graphics are presented without explanation.

(e) Captions used for graphics
2 Explanatory captions with all or nearly all illustrations and graphics.
1 Brief captions used for some illustrations and graphics.
0 Captions are not used.

4. LAYOUT AND TYPOGRAPHY

(a) Layout factors
2 At least five of the following eight factors are present:
    1. Illustrations are on the same page adjacent to the related text.
    2. Layout and sequence of information are consistent, making it easy for the patient to predict the flow of information.
    3. Visual cuing devices (shading, boxes, arrows) are used to direct attention to specific points or key content.
    4. Adequate white space is used to reduce appearance of clutter.
    5. Use of color supports and is not distracting to the message. Viewers need not learn color codes to understand and use the message.
    6. Line length is 30-50 characters and spaces.
    7. There is high contrast between type and paper.
    8. Paper has nongloss or low-gloss surface.
1 At least three of the superior factors are present.
0 (1) Two (or less) of the superior factors are present.
    (2) Looks uninviting or discouragingly hard to read.

SAM   3

44

FACTOR TO BE RATED	SCORE	COMMENTS

(b) Typography
2 The following four factors are present:
    1. Text type is in uppercase and lowercase serif (best) or sans-serif.
    2. Type size is at least 12 point.
    3. Typographic cues (bold, size, color) emphasize key points.
    4. No ALL CAPS for long headers or running text.
1 Two of the superior factors are present.
0 One or none of the superior factors are present.
   Or, six or more type styles and sizes are used on a page.

(c) Subheads ("chunking") used
2 (1) Lists are grouped under descriptive subheadings or "chunks."
    (2) No more than five items are presented without a subheading.
1 No more than seven items are presented without a subheading.
0 More than seven items are presented without a subheading.

5. LEARNING STIMULATION, MOTIVATION

(a) Interaction used
2 Problems or questions presented for reader responses.
1 Question-and-answer format used to discuss problems and solutions (passive interaction).
0 No interactive learning stimulation provided.

(b) Behaviors are modeled and specific
2 Instruction models specific behaviors or skills.
   (For example, for nutrition instruction, emphasis is given to changes in
   eating patterns or shopping or food preparation/cooking tips; tips to read labels.)
1 Information is a mix of technical and common language that the reader
   may not easily interpret in terms of daily living (for example: Technical:
   Starches-80 calories per serving; High Fiber-1-4 grams of fiber in a serving).
0 Information is presented in nonspecific or category terms such as the food groups.

(c) Motivation, self-efficacy
2 Complex topics are subdivided into small parts so that readers may experience
   small successes in understanding or problem solving, leading to self-efficacy.
1 Some topics are subdivided to improve the readers' self-efficacy.
0 No partitioning is provided to create opportunities for small successes.

FACTOR TO BE RATED	SCORE	COMMENTS

6. CULTURAL APPROPRIATENESS

(a) Match in logic, language, experience (LLE)
2 Central concepts/ideas of the material appear to be culturally
     similar to the LLE of the target culture.
1 Significant match in LLE for 50 percent of the central concepts.
0 Clearly a cultural mismatch in LLE.

_____

(b) Cultural image and examples
2 Images and examples present the culture in positive ways.
1 Neutral presentation of cultural images or foods.
0 Negative image such as exaggerated or caricatured cultural characteristics, actions, or examples.

_____

Total SAM score:
The maximum possible total score is 44 points (100 percent).

_____

44   **(maximum possible score)**

minus   **# N/A** _____ **x 2 =** _____ **(revised maximum score)**

Total SAM score _____ **/ revised maximum score** _____ **= Percent score:** _____**%**

Interpretation of SAM percentage ratings:
70-100 percent   superior material
40-69 percent   adequate material
 0-39 percent   not suitable material

SAM   5

Appendix B Websites Included in SAM Analysis

Appendix Table 1.

Website Name	Sponsor	URL
Genetic Counseling	CDC	https://www.cdc.gov/genomics/gtesting/genetic_counseling.htm
Genetic Counseling	National Human Genome Research Institute	https://www.genome.gov/genetics-glossary/Genetic-Counseling
What is Genetic Testing?	MedlinePlus (National Library of Medicine)	https://medlineplus.gov/genetics/understanding/testing/genetictesting/
Genetic Testing	CDC	https://www.cdc.gov/genomics/gtesting/genetic_testing.htm
Genetic Testing	National Human Genome Research Institute	https://www.genome.gov/genetics-glossary/Genetic-Testing
Genetic Testing	CDC	https://www.cdc.gov/genomics/gtesting/genetic_testing.htm
What are the benefits of genetic testing?	MedlinePlus (National Library of Medicine)	https://medlineplus.gov/genetics/understanding/testing/benefits/
What happens during a genetic consultation?	MedlinePlus (National Library of Medicine)	https://medlineplus.gov/genetics/understanding/consult/expectations/
Genetic Counseling Graduate Program	Cincinnati Children's Hospital	https://www.cincinnatichildrens.org/education/clinical/student-grad/genetic-counseling/prospective-students
Genetic Testing	Mayo Clinic	https://www.mayoclinic.org/tests-procedures/genetic-testing/about/pac-20384827
Genetic Testing (For Parents)	Nemours KidsHealth	https://kidshealth.org/en/parents/genetics.html
Genetic Testing	Mayo Clinic	https://www.mayoclinic.org/tests-procedures/genetic-testing/about/pac-20384827

What to expect when meeting with a genetic counselor	Cancer.Net (American Society of Clinical Oncology)	https://www.cancer.net/navigating-cancer-care/cancer-basics/genetics/what-expect-when-meeting-genetic-counselor
Genetic Counseling (For Parents)	Nemours KidsHealth	https://kidshealth.org/en/parents/genetic-counseling.html
Frequently asked questions about genetic counseling and testing	University of Iowa Hospitals and Clinics	https://uihc.org/health-topics/frequently-asked-questions-about-genetic-counseling-and-testing
How to prepare for genetic counseling	Breastcancer.org	https://www.breastcancer.org/genetic-testing/what-to-expect
About Genetic Counselors	NSGC	https://www.nsgc.org/About/About-Genetic-Counselors
What to expect when meeting with a genetic counselor	Cancer.Net (American Society of Clinical Oncology)	https://www.cancer.net/navigating-cancer-care/cancer-basics/genetics/what-expect-when-meeting-genetic-counselor
Making Smart Decisions about Genetic Testing	Choosing Wisely (ACMG)	https://www.choosingwisely.org/patient-resources/making-smart-decisions-about-genetic-testing/
Genetic Testing: What You Should Know	familydoctor.org (American Academy of Family Physicians)	https://familydoctor.org/genetic-testing-what-you-should-know/

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