

Analyzing readability and suitability of webpages related to genetic counseling and genetic testing

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Madalyn Charnego

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This thesis was presented

by

Madalyn Charnego

It was defended on

April 7, 2023

and approved by

Dr. Elizabeth Felter, DrPH, MCHES, Assistant Professor, Behavioral and Community Health Sciences

Ms. Christine Munro, MS, MPH, CGC, Adjunct Professor, Human Genetics, Director of Recruitment and Admissions, Genetic Counseling Program

Thesis Advisor Director: Dr. Andrea Durst, MS, DrPH, CGC, Assistant Professor, Human Genetics, Vice Chair for Practice, Associate Director, Genetic Counseling Program, Director, MPH in Public Health Genetics

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Madalyn Charnego, MS, MPH

University of Pittsburgh, 2023

Background and Objective Web-based resources are often used by patients referred for genetic counseling to gather information prior to their appointment; however, many health care materials are written in excess of recommended reading levels. Little is known about their readability and suitability. This study aims to determine the readability and suitability of commonly accessed webpages and if there is a difference in these metrics depending on which type of organization (i.e., government, non-profit organization) authored the webpage.

Methods Twenty webpages were identified using Google. Searches of the questions “What is a genetic counselor?”, “What is genetic testing”, “Why do I need genetic testing?”, and “What happens at a genetic counseling appointment?” were completed and the top 5 pages were from each. These webpages were then analyzed using Readable.com (Flesch-Kincaid and Standardized Measure of Gobbledygook scores) and the Suitability Assessment of Materials (SAM). To complete the SAM analysis, two reviewers completed the tool for each webpage. Sponsor type was determined based on the primary goal of the group that supported or published the webpage.

Results The average Flesch-Kincaid scores for the websites were between 8th and 12th grade. The average Standardized Measure of Gobbledygook scores were between 11th and 14th grade. The majority of webpages rated as adequate on the SAM scale.

Conclusion The webpages assessed through this study were above the recommended reading grade level of 6th to 8th grade. The webpages and were noted to be adequately suitable for the general population regarding the presentation and accessibility of information. The results of this study highlight the continued need for evaluation of patient resources, especially those on the internet, to ensure they are meeting the needs of the rising number of individuals being referred to genetic services. Results of this study further support the work being generated through Healthy People 2030 and the continued public health efforts to reduce health disparities related to low health literacy.

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Preface

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1.0 Introduction

Health literacy is defined as “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” (“Health Literacy in Healthy People 2030,”). Studies have shown that the average individual in the United States reads at or below a eighth grade level (Safeer, 2005). In response to the low health literacy in America, the American Medical Association (AMA) recommended that health care materials be written at a sixth grade reading level (Weiss, 2003). Similarly, the National Institutes of Health (NIH) have recommended materials be written at a grade level no higher than eighth grade (Ridpath JR, 2007). However, most healthcare materials have been found to be written or presented at or above the tenth-grade level (Safeer, 2005). Low health literacy levels lead to poorer health outcomes. For example, individuals with low health literacy are more likely to mismanage chronic conditions due to improper medication usage, reluctance to follow up with the proper health professionals, and uncertainty of what their condition means for their health (Safeer, 2005).

Reading levels of print materials can be measured by scales, including but not limited to the Flesch-Kincaid (FK) scale and the Standardized Measure of Gobbledygook (SMOG) scale. The FK scale analyzes text to determine its reading ease based on the average length of a sentence and the average number of syllables per word. The SMOG conducts its measurement of reading ease based only on complex words (Mc Laughlin, 1969). In addition to grade level readability, resources can also be measured for suitability. One tool that is used for this measurement is the Suitability Assessment of Materials (SAM). This tool has a primary focus of determining if a

resource is suitable and accessible to the population at hand by assessing layout, graphics, content, literacy, learning motivation, and cultural appropriateness (Doak, 1996a).

In the field of genetic counseling, patients seeking out the web for resources prior to coming in for genetic counseling and testing is common. Patients may encounter web-based resources from entities such as the National Society of Genetic Counselors, the Centers for Disease Control and Prevention, health care systems, and nonprofit organizations. To the best of our knowledge, there has not been analysis of readability and suitability of webpages related to genetic counseling and genetic testing. Previous work has shown that webpages related to health conditions are written well above the average reading level for the general population (Guan, Maloney, Roter, & Pollin, 2018). Similarly, Guan et al showed that more than one third of sites analyzed did not meet criteria considered to be suitable based on SAM. Until now, most analysis has been focused on disease specific webpages, and there has not been a global analysis of webpages related to genetic counseling and genetic testing.

This project will analyze webpages related to genetic testing and genetic counseling that would commonly be searched by patients recently referred for genetic services. A set of 20 webpages was selected through a Google search by taking the top five search results from four searches of the following questions:

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?

These questions were determined by the authors to be common questions patients referred for genetic counseling may search.

1.1 Specific Aims

1. To analyze the FK and SMOG reading ease of a set of 20 webpages and compare them to the recommended reading level of sixth to eighth grade.
2. To utilize the SAM to determine if the set of webpages contains information suitable for the audience.
3. To determine if websites from different sources differ in their readability and suitability.

2.0 Manuscript

2.1 Background

In 2003, the National Center for Education Statistics (NCES) launched the most recent version of the National Assessment of Adult Literacy (NAAL) to determine the general English literacy level of adults in the United States. The study consisted of analyzing more than 19,000 adults in various living conditions, including prisons. While the study was centered around general English literacy, there was a section that focused on health literacy skills for adults in the United States (Kutner, 2006). NAAL found that around 53% of adults had intermediate health literacy. However, 36% of adults had basic or below basic health literacy (Kutner, 2006). Health literacy levels have been reported to correlate to health outcomes in many individuals (Schillinger, 2020). Low health literacy throughout the United States continues to be a major public health crisis. (Schillinger, 2020). In response to this crisis, both the American Medical Association (AMA) and the National Institutes of Health (NIH) created suggested reading level guidelines. AMA recommends healthcare materials be written at a sixth grade level, whereas the NIH recommends no greater than eighth grade (Ridpath JR, 2007; Weiss, 2003).

Health literacy levels have been reported to correlate to poor health outcomes in many individuals. Adults with low health literacy generally have poorer overall health, higher rates of chronic disease, and higher mortality rate than their counterparts with high health literacy (Schillinger, 2020). Low health literacy levels have been associated with an increased risk of misusing medication or not adhering to medications properly. Similarly, studies have shown that individuals with higher health literacy were more likely to practice better techniques with

medications like inhalers that have a multi-step use process (Dewalt, Berkman, Sheridan, Lohr, & Pignone, 2004). In relation to screening and prevention measures, like Pap smears or mammograms, individuals with lower health literacy had greater odds of not participating in preventative screenings (Schillinger, 2020). Also, lower health literacy has been correlated to not receiving preventative vaccinations, such as the influenza vaccine or pneumococcal vaccines (Dewalt et al., 2004). Overall, lower health literacy has been significantly associated with a higher likelihood of hospitalization. Odds of hospitalization in low health literacy groups, when controlled for all other factors, is around 2 times higher than that seen in high health literacy groups (Dewalt et al., 2004). The American Medical Association (AMA) notes that individuals with lower health literacy may exhibit specific behaviors that could be seen as red flags. Specifically, the AMA sites a lack of follow through for laboratory tests and referrals to specialists or other consultants (Weiss, 2003).

There is limited information surrounding the public's understanding of genetic counselors and the benefits of meeting with them. In one study, around 36% of genetic counselors surveyed cited a lack of knowledge or understanding of the value of genetic counseling as being a factor in patients not following through with a referral to a genetic counselor (Rolnick, 2011). A study conducted in Canada found that 69% of individuals surveyed from the general population had not heard of genetic counseling (Maio, Carrion, Yaremco, & Austin, 2013). Individuals in this survey also noted what they thought to be the purpose of genetic counseling. Up to 75% of those surveyed felt that the main purpose of genetic counseling was to "prevent genetic disease or abnormalities" (Maio et al., 2013) Interestingly, people who had not heard of genetic counseling felt that genetic counseling should be completed by "a healthcare provider specifically trained in genetic counseling" rather than another type of provider (Maio et al., 2013).

According to Pew Internet Usage and American Life, around 93% of the United States population utilizes the internet to search for information (*Internet/Broadband Fact Sheet*, 2021). Of those individuals that utilize the internet, many use it to self-educate on health-related information. This internet usage as it relates to health care has been given the name of “e-health” (Maloney, Ilic, & Green, 2004). As e-health has become more prevalent in the United States and around the world, several studies have examined if web-based material is relevant to and appropriate for public consumption. In many of the studies reviewed, the authors employed a method of multiple internet searches to develop a list of web-based material for analysis. In some studies, the list was generated by searching the same terms across multiple search engines (Finnie, Felder, Linder, & Mullen, 2010; Guan et al., 2018). The other major method of generating a list of web-pages was to search multiple questions or terms, but only using one search engine, most often Google (Marsh, Dobbs, & Hutchings, 2020; Rhee, Von Feldt, Schumacher, & Merkel, 2013). Additionally, the composition of the list of web-pages consisted of the top 5 sites from the searches (Marsh et al., 2020; Rhee et al., 2013). The main two scoring tools used for reading ease were FK and SMOG. Sites, like Readable.com, were used to calculate reading ease (Marsh et al., 2020). Additionally, the SAM scale was used across many studies reviewed. The primary goal was to determine if the materials presented were appropriate for a pre-determined audience, such as patients or families of individuals with a specific condition.

To date, there has been limited analysis of the readability and suitability of web-based resources for health information. In a study of web resources on monogenic diabetes, all websites analyzed were above a sixth-grade level. In contrast, the majority of websites had either an adequate or superior rating on suitability analysis (Guan et al., 2018). Guan et al concluded that while these resources may be presented in an adequate manner for patients, they are not

comprehensible from a reading level standpoint. A study of resources for PKU, which utilized multiple measures of readability, identified that the median readability was around grade ten for the five websites analyzed (Marsh et al., 2020). The five webpages analyzed by Marsh et al had a variety of sponsors, including government, healthcare systems, and non-profits. Based on readability, this study concluded that patients should seek information specifically from government or non-profit websites (Marsh et al., 2020). A 2017 study of webpages related to skin cancer found similar reading level conclusions. All of the ten most commonly accessed resources were written above the recommended sixth grade level (Dobbs, Neal, Hutchings, Whitaker, & Milton, 2017). An additional study that analyzed readability and suitability of resources for rheumatic diseases found that all twenty-three of the resources evaluated had readability scores above eighth grade level. SAM scores in this study noted that a majority of resources were adequately rated, however there were five resources that were superior (Rhee et al., 2013).

The results generated from these studies further support the conclusion that many healthcare materials are written at or above a tenth grade reading level (Safeer, 2005). They also highlight that the issue of poor readability transcends multiple health conditions and concerns. Additionally, the suitability outcomes propose that a majority of healthcare information on the internet is only considered adequate for the general population in terms of SAM metrics. However, the studies noted here are all specific to one condition or a group of conditions. To the study team's knowledge, there has not been broad analysis of information related to genetic testing or genetic counseling at this time.

This study aims to analyze the FK and SMOG reading ease of a set of 20 webpages and compare them to the recommended reading level of sixth to eighth grades. Secondly, this study aims to utilize SAM to determine if the set of webpages contains information that is suitable for

the audience. Finally, this study aims to determine if websites from different sponsor sources differ in their readability and suitability.

2.2 Methods

This study was determined not to be human subjects research by the University of Pittsburgh Institutional Review Board as shown in Appendix A.

2.2.1 Collection of Webpages

Following similar methods in previous studies, the collection of webpages was based on a set of internet searches (Dobbs et al., 2017; Finnie et al., 2010; Guan et al., 2018; Marsh et al., 2020; Rhee et al., 2013). Webpages were collected using an Incognito Search on Google.com. An Incognito Search was necessary to remove any previous search history bias. Because webpage rankings can be updated over time, webpage rankings were recorded on March 22, 2022.

To generate the list of 20 webpages, Google searches of four questions were completed and the top five webpages for each were noted. Webpages that were duplicated among the question searches were kept in the ranking in order to best simulate the information a patient may access. The four questions below were determined by the authors to represent common questions that individuals referred for genetic counseling services may be interested in searching. The questions were:

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?

A full list of the webpages can be found in Appendix B.

2.2.2 Determination of Sponsor Type

Sponsor types were determined for each of the 20 webpages. To label each webpage with a category, the primary purpose of the organization or entity responsible for the webpage was used. For example, if a webpage was sponsored by the Centers for Disease Control (CDC), this page was a government sponsored page since the CDC is a government entity. Similarly, pages that came from healthcare systems were noted as such. Pages that originated from sites sponsored by professional organizations were also documented. Nonprofit sponsors were determined to be advocacy or patient support groups.

2.2.3 Readability Scores

Reading ease can be evaluated on a variety of scales. One of the most common, and widely utilized scales, is the Flesch-Kincaid (FK) scale for determining reading ease. Readability of materials is determined by two variables in the FK scale: average sentence length (based on number of words) and average word length (based on syllables) (Jindal & MacDermid, 2017). The FK scale is generally considered valid for materials that fall within the grade 5 to college level reading ease. However, in comparison to other formulas, FK is often considered to provide lower estimates of readability (Jindal & MacDermid, 2017). Because of the consideration that FK has

for syllable count when considering length of words, medical information is often found to have lower reading ease. Common medical terminology like “hypertension” or “diabetic” that have a high number of syllables and usage of these words in patient materials causes the reading level to fall in the fairly difficult to difficult range. Although this is a strong limitation for the use of FK, the wide availability of the FK scale makes it a feasible choice for understanding reading ease.

The SMOG reading ease grading scale is more valid than previously created reading scales, including FK (Mc Laughlin, 1969). SMOG scores are based on two factors: First, the number of polysyllabic words within a set of 30 sentences (to assess of the reading difficulty of text); second, there is an easily used formula to convert the number of polysyllabic words into a reading grade. Previous studies have shown that SMOG scoring is more reliable than FK. In a 2013 study, SMOG was the most consistent scoring system across multiple sample texts (Wang, Miller, Schmitt, & Wen, 2013). When compared directly, FK and SMOG scores differed, with FK providing a lower estimate of grade level. Similarly, SMOG calculations only showed variation of up to two grade levels compared with other reading ease estimate tools (Wang et al., 2013). Previous studies also determined that SMOG was the most effective grading tool for health care materials. This was based, in part, on the fact that SMOG was built from the most recent grading criteria and is validated against 100% comprehension (Mc Laughlin, 1969; Wang et al., 2013).

Reading ease and reading grade level were analyzed using Readable.com. Readable.com is an online reading ease calculator that compiles the reading grade level and other readability scores on multiple scales. For the purposes of this study, the FK grade level and SMOG score were reported for each website. FK scores were used because of the wide availability of reading ease tools that use FK. SMOG scores were used because it has been shown to be a better metric for scientific and health care materials (Wang et al., 2013). To generate the values, all body text from

the webpages was copied and pasted into the Readable.com platform. For pages that included videos or graphics, transcripts and other text were copied in lieu of traditional body text. Those values were then averaged across question and sponsor type.

2.2.4 Suitability Assessment

The Suitability Assessment of Materials (SAM) was created by Doak, Doak, Miller, and Wilder in 1994 as part of a Johns Hopkins School of Medicine Study on nutritional education in African Americans (Doak, 1996a). The SAM was developed out of a need for health care providers to evaluate their healthcare instruction systematically and quickly for different audiences. SAM has been applied to determine suitability of video and audio as well. SAM provides scores of superior, adequate, or not suitable based on a set of 6 criteria: content, literacy demand, graphics, layout, and typography, learning stimulation and motivation, and cultural appropriateness. (Doak, 1996) The SAM framework addresses the aspects of accessibility of materials that traditional reading ease or appropriateness measures do not account for. By providing a numerical rating to the categories listed above, healthcare providers and other professionals can assess written documents both in print and online (Doak, 1996a).

Each webpage was evaluated using those 6 criteria by two primary raters. A third rater was brought in to evaluate webpages with discrepant scores. A score was considered to be discrepant if both original raters did not agree on the same score category (not suitable, adequate, or superior). Afterwards, meeting was held to come to consensus on the majority rating for webpages. A score sheet, , was used by each rater to maintain consistency. The score sheet used can be found in chapter 4 of “Teaching Patients with Low Literacy Skills” which is accessible via The Harvard T.H. Chan School of Public Health: Health Literacy Studies Web Site (Doak, 1996b). To evaluate

the criteria of readability, the FK score was used for all websites, regardless of differences between FK and SMOG scores for webpages. In order to prevent webpages undergoing updates during evaluation, all SAM scores were determined during October 2022, and screenshots were taken in case reanalysis was necessary. Reported SAM rating for each webpage was assigned based on majority rating. As shown on the score sheet, the webpages each received a score of either Not Suitable, Adequate, or Superior based on their total score calculation (Doak, 1996b).

2.2.5 Statistical Analysis

Average statistics were calculated using Microsoft Excel. Statistical analysis was completed using Stata to determine if there was a significant difference between the reading levels associated with webpages from each sponsor type and within each question group. A one-way ANOVA test was utilized to compare both FK and SMOG scores.

2.3 Results

Analysis of the 20 webpages was completed for each question type and sponsor type (Table 1). Similarly, average statistics were calculated for all 20 pages together. The average FK grade level for the set of 20 pages was 10.84. The average SMOG level for the set of 20 pages was 13.66. Both grade level scores were above the recommendation of sixth to eighth grade reading level.

Table 1 Compiled information for all webpages

Webpage Title	Sponsor	Sponsor Type	Year of Last Update	Questions	FK Score	SMOG Score	SAM Score
---------------	---------	--------------	---------------------	-----------	----------	------------	-----------

(At Time of Collection)							
Genetic Counseling ("Genetic Counseling," 2020)	CDC	Government	2020	What is a genetic counselor	12.7	14.6	Adequate
Genetic Counseling ("Genetic Counseling," 2022)	National Human Genome Research Institute (NHGRI)	Government	2022	What is a genetic counselor	17.5	19.7	Adequate
Genetic Counseling Graduate Program ("Genetic Counseling Graduate Program," n.d.)	Cincinnati Children's Hospital	Healthcare	None Listed	What is a genetic counselor	13.7	14.6	Adequate
About Genetic Counselors ("About Genetic Counselors," n.d.)	National Society of Genetic Counselors	Professional Organization	None Listed	What is a genetic counselor	12.9	15.9	Adequate
What to expect when meeting with a genetic counselor ("What to Expect When Meeting With a Genetic Counselor," 2021)	American Society of Clinical Oncology	Professional Organization	2021	What is a genetic counselor What happens at a genetic counseling appointment	8.9	12.3	Superior
What is genetic testing? ("What is genetic testing?," 2021)	MedlinePlus	Government	2021	What is genetic testing	12.3	15.8	Adequate
Genetic Testing ("Genetic Testing," 2020b)	CDC	Government	2020	What is genetic testing Why do I need genetic testing	9.7	12.8	Superior
Genetic Testing ("Genetic Testing," 2022)	NHGRI	Government	2022	What is genetic testing	13.7	16.3	Adequate
Genetic Testing ("Genetic Testing," 2020a)	Mayo Clinic	Healthcare	2020	What is genetic testing	10.6	13.6	Adequate

				Why do I need genetic testing			
Genetic Testing (For Parents) (Anzilotti, 2021b)	Nemours KidsHealth	Healthcare	2021	What is genetic testing	6.9	10.5	Superior
What are the benefits of genetic testing ("What are the benefits of genetic testing," 2021)	MedlinePlus	Government	2021	Why do I need genetic testing	11.4	13.4	Adequate
Making smart decisions about genetic testing ("Making Smart Decisions About Genetic Testing," 2015)	American College of Medical Genetics	Professional Organization	2015	Why do I need genetic testing	6.8	10.6	Superior
Genetic Testing: What you should know ("Genetic Testing: What You Should Know," 2020)	American Academy of Family Physicians	Professional Organization	2020	Why do I need genetic testing	5.4	9.5	Adequate
What happens during a genetic consultation ("What happens during a genetic consultation," 2021)	MedlinePlus	Government	2021	What happens at a genetic counseling appointment	13	14.6	Adequate
Genetic Counseling (For Parents) (Anzilotti, 2021a)	Nemours KidsHealth	Healthcare	2021	What happens at a genetic counseling appointment	13.3	14.9	Adequate
Frequently asked questions about genetic counseling and testing ("Frequently asked questions about genetic counseling and testing," 2016)	University of Iowa Hospitals and Clinics	Healthcare	2017	What happens at a genetic counseling appointment	11.7	14.8	Adequate
How to prepare for genetic counseling ("How To Prepare for Genetic	Breastcancer.org	Nonprofit	2020	What happens at a genetic counseling appointment	11	14.1	Adequate

2.3.1 What is a Genetic Counselor?

The five websites generated from the search question “What is a genetic counselor”, included information from government, healthcare, and professional organization sponsors. The highest FK grade level reported was 13.7 from the Cincinnati Genetic Counseling Graduate Program webpage (“Genetic Counseling Graduate Program,” n.d.). This webpage was created mainly to inform individuals interested in becoming a genetic counselor, not those in the general public. The lowest FK grade level reported was 8.9 from “What to expect when meeting with a genetic counselor” page (“What to Expect When Meeting With a Genetic Counselor,” 2021). For this question, all the recorded FK grade levels were above the recommended level of 6th-8th grade. Most of the webpages were at the high school/early college, or difficult/fairly difficult level of the scale (table 2). The average FK score for this question was 12.34. This was the highest FK score among the questions.

The pages were then scored based on the SMOG scale, also shown in table 2. The highest SMOG score reported was 16.1 from the National Human Genome Research Institute (“Genetic Counseling,” 2022). The lowest SMOG score reported was 12.3 from the American Society of Clinical Oncology’s webpage (“What to Expect When Meeting With a Genetic Counselor,” 2021). The average SMOG score was 14.7. This was the highest SMOG score among the question groups. Similar to the FK grade levels, the SMOG scores were all well above the recommended grade level of 6th to 8th grade.

All but one webpage from this search had an adequate SAM score. The single superior page was “What to expect when meeting with a genetic counselor” from the American Society of Clinical Oncology ("What to Expect When Meeting With a Genetic Counselor," 2021). Overall, the webpages from this search are appropriate for a general audience in terms of suitability.

Table 2. Scores for "What is a genetic counselor?"

Webpage Name (Sponsor)	FK Grade Level	SMOG Score	SAM Score
Genetic Counseling (CDC)	12.7	14.6	Adequate
Genetic Counseling Graduate Program (Cincinnati Children’s Hospital)	13.7	14.6	Adequate
About Genetic Counselors (National Society of Genetic Counselors)	12.9	15.9	Adequate
Genetic Counseling (National Human Genome Research Institute)	13.5	16.1	Adequate
What to Expect when Meeting with a Genetic Counselor (American Society of Clinical Oncology)	8.9	12.3	Superior

2.3.2 What is Genetic Testing?

The FK grade level for each webpage in this set is shown in table 3. This question search included information sponsored by government and healthcare groups. The highest FK grade level for this set was from the Genetic Testing page sponsored by the National Human Genome Research Institute at 13.7 ("Genetic Testing," 2022). The lowest grade level reported was 6.9 from the Genetic Testing page sponsored by Nemours KidsHealth (Anzilotti, 2021b). This is within the recommended 6th to 8th grade reading level and is the only website from this search to meet this

criterion. Most of the other webpages for these questions were at the late high school/ early college level, or the difficult/ fairly difficult category. The average FK score for this group was 10.64.

The pages were then scored based on the SMOG scale, also shown in Table 3. The highest SMOG grade level reported was 16.3 from National Human Genome Research Institute ("Genetic Testing," 2022). The lowest SMOG grade level was 10.5 from Nemours KidsHealth (Anzilotti, 2021b). The average SMOG score was 13.8. Similar to the FK grade levels, the pages listed were all above the recommended 6th to 8th grade level.

Three out of five webpages in this search scored adequate on the SAM. Two webpages, "What is genetic testing" from the CDC and "Genetic testing" from Nemours KidsHealth scored superior (Anzilotti, 2021b; "What is genetic testing?," 2021). Overall, the webpages in this search were appropriate for the general population.

Table 3. Scores for "What is genetic testing?"

Webpage Name (Sponsor)	FK Grade Level	SMOG Score	SAM Score
What is Genetic Testing (MedlinePlus)	12.3	15.8	Adequate
What is genetic testing (CDC)	9.7	12.8	Superior
Genetic Testing (Mayo Clinic)	10.6	13.6	Adequate
Genetic Testing (National Human Genome Research Institute)	13.7	16.3	Adequate
Genetic Testing (Nemours KidsHealth)	6.9	10.5	Superior

2.3.3 Why do I Need Genetic Testing?

For websites in the top five search returns for this question, two scored within the recommended 6th to 8th grade reading level on the FK grade level analysis: "Making smart decisions about genetic testing" (6.8) and "Genetic Testing: What you should know" (5.4)

("Genetic Testing: What You Should Know," 2020; "Making Smart Decisions About Genetic Testing," 2015). Both of these websites were created by professional organizations. Upon analysis by SMOG, however, all of the websites were found to have reading levels above the 8th grade level, with a range between 9.5 and 13.6 (table 4). The average FK score was 8.78 and the average SMOG score was 11.98. These were the lowest averages amongst the question groups.

Of the five webpages, 2 pages scored superior on SAM. These pages were "Genetic testing" from the CDC and "Making smart decisions about genetic testing" from the American College of Medical Genetics ("Genetic Testing," 2020b; "Making Smart Decisions About Genetic Testing," 2015). The other three webpages were rated as adequate. Overall, the webpages from this search were suitable for the general public.

Table 4. Scores for "Why do I need genetic testing?"

Webpage Name (Sponsor)	FK Grade Level	SMOG Score	SAM Score
Genetic Testing (CDC)	9.7	12.8	Superior
What are the Benefits of Genetic Testing (Medline Plus)	11.4	13.4	Adequate
Genetic Testing (Mayo Clinic)	10.6	13.6	Adequate
Making Smart Decisions About Genetic Testing (American College of Medical Genetics)	6.8	10.6	Superior
Genetic Testing: What You Should Know (American Academy of Family Physicians)	5.4	9.5	Adequate

2.3.4 What Happens at a Genetic Counseling Appointment?

As shown in table 5, the FK grade level was computed for each page. The highest FK grade level was 13.3. This was reported from a page sponsored by Nemours KidsHealth (Anzilotti, 2021a). The lowest FK grade level was 8.9. This was reported from a page sponsored by the

American Society of Clinical Oncology ("What to Expect When Meeting With a Genetic Counselor," 2021). All the pages in this question category were above the recommended 6th to 8th grade reading level. The average FK score was 11.58.

Also shown in table 5 , the SMOG scores were analyzed for each page. The highest SMOG score reported was 14.8 from page sponsored by University of Iowa Hospitals and Clinics ("Frequently asked questions about genetic counseling and testing," 2016). The lowest SMOG grade level was 12.3 from the American Society of Clinical Oncology ("What to Expect When Meeting With a Genetic Counselor," 2021). The average SMOG score was 14.14. Similar to the FK scores, all the SMOG grade levels were above the recommended 6th to 8th grade level.

Four out of five webpages for this question were rated as adequate through the SAM. One webpage, "What to expect when meeting with a genetic counselor" from the American Society of Clinical Oncology, ranked as superior ("What to Expect When Meeting With a Genetic Counselor," 2021). Overall, all five of the webpages were suitable for a general audience.

Table 5. Scores for "What happens at a genetic counseling appointment?"

Webpage Name (Sponsor)	FK Grade Level	SMOG Score	SAM Score
What to Expect When Meeting with a Genetic Counselor (American Society of Clinical Oncology)	8.9	12.3	Superior
What Happens During a Genetic Consultation (Medline Plus)	13	14.6	Adequate
Genetic Counseling- For Parents (Nemours KidsHealth)	13.3	14.9	Adequate
How to Prepare for Genetic Counseling (Breastcancer.org)	11	14.1	Adequate
Frequently Asked Questions About Genetic Counseling and Testing (University of Iowa Hospitals and Clinics)	11.7	14.8	Adequate

2.3.5 Average Values per Question

Shown in Table 6, a comparison of the average FK and SMOG scores across the questions was completed. The highest average FK and SMOG was 12.34 and 14.7 from the question “What is a genetic counselor.” The lowest FK and SMOG score was 8.78 and 11.98 from the question “why do I need genetic testing.” When comparing the averages using a one-way ANOVA, there was not a statistically significant difference between the question groups (Tables 7 and 8). In other words, while there were some question groups that had slightly better reported readability, there is no difference between the highest and lowest scores of the question groups.

Table 6. Average FK and SMOG scores per question group

Question Group	FK Grade Level	SMOG Score
What is a genetic counselor	12.34	14.7
What is genetic testing	10.64	13.8
Why do I need genetic testing	8.78	11.98
What happens at a genetic counseling appointment	11.58	14.14

Table 7. One-way ANOVA comparing FK scores across question groups

Source	Partial SS	Df	MS	Prob>F
Model	49.8455	3	16.615167	0.0905
Question	49.8455	3	16.615167	0.0905
Residual	103.42	16	6.46375	

Total	153.2655	19	8.0666053
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Table 8. One-way ANOVA comparing SMOG scores across question group

Source	Partial SS	Df	MS	Prob>F
Model	30.2375	3	10.079167	0.1151
Question	30.2375	3	10.079167	0.1151
Residual	69.788	16	4.36175	
Total	100.0255	19	5.2645	

2.3.6 Averages Values per Sponsor Type

As shown below in Table 9, there were 4 different sponsor types represented in the webpages. The average FK grade level score for each sponsor type is shown in Table 9. The highest grade level was seen in the government sponsored sites, with an average of 12. This sponsor type also had the highest SMOG score among the groups at 14.55. The lowest FK grade level was 8.5. This was from the Professional Organization group. This group also had the lowest SMOG score at 12.08. All of the FK and SMOG average scores were above the 6th to 8th grade recommendation. Additionally, one-way ANOVAs were completed to compare FK and SMOG scores between the sponsor groups (Tables 10 and 11). A comparison of the FK scores between the sponsor groups was not statistically significant at a p value of 0.1348. Similarly, the comparison of SMOG scores between the sponsor groups was not statistically significant either (p=0.2097).

Table 9. Average scores per sponsor type

Sponsor Type	Count	FK Grade Level	SMOG Score
Government	7	12	14.55
Healthcare	5	10.81	13.47
Professional Organization	4	8.5	12.08
Nonprofit	1	11	14.1

Table 10. One-way ANOVA comparing FK scores between sponsor types

Source	Partial SS	Df	MS	F	Prob>F
Model	49.367	3	16.456	2.22	0.1348
Sponsor Type	49.367	3	16.456	2.22	0.1348
Residual	96.472	13	7.421		
Total	1445.839	16	9.115		

Table 11 One-way ANOVA comparing SMOG score between sponsor types

Source	Partial SS	Df	MS	F	Prob>F
Model	27.436	3	9.145	1.73	0.2097
Sponsor Type	27.436	3	9.145	1.73	0.2097
Residual	68.644	13	5.280		
Total	96.08	16	6.005		

2.4 Discussion

Although the internet is a wide source of information, there are many barriers to accessing health information through the internet. There is considerable concern that the information is not written at appropriate reading levels or presented in a suitable manner for the general public. The average reading grade level in the United States is between a sixth and eighth grade level (Kutner, 2006). Meanwhile, a majority of healthcare and health related materials are written at grade levels closer to tenth grade or above (Safer, 2005). In comparing the average FK and SMOG scores across

each question, all average scores were above the eighth-grade level. A previous study published in 2013 compared the readability and appropriateness of various print and web-based resources for rheumatic disease patients. A total of 23 resources were evaluated and all were found to have reading levels above eighth grade (Rhee et al., 2013). Similar results were found in the evaluation of webpages for this project.

When comparing SMOG and FK scores in this study, SMOG scores were higher than FK scores for all webpages. This is consistent with previous determinations of scoring differences between FK, SMOG, and other readability calculations (Wang et al., 2013). A study of online patient education materials focused on ophthalmology previously noted that SMOG scores were between 12.9 and 17.7 (Huang et al., 2015). This study found that the lowest SMOG score was 9.5, and the highest SMOG score was 16.3. However, 9.5 was an outlier in the data. The majority of the SMOG scores in this study were above 11. The conclusion from the Huang et al study was that online patient education materials were not written at appropriate reading levels. The SMOG and FK scores in this data set corroborate this conclusion.

When analyzing the suitability of webpages, none of the webpages were in the “not suitable” category. A not suitable webpage is missing a majority of the SAM components or does not use each component appropriately. A majority of webpages were rated as “adequate” by the raters. An adequate rating indicates that webpages had some of the appropriate features, such as graphics, bullet point lists, white space, or motivational language, but did not meet all of the components of SAM, but this means that overall, the general population can utilize these sources and gain information appropriately. A common rating of adequate is in line with findings from previous studies. Rhee et al found that the online patient materials related to rheumatic disease analyzed in their study rated as adequately suitable for their population (Rhee et al., 2013).

Interestingly, there were webpages that were rated as “superior.” These webpages had features that made their information more accessible and understandable to patients, including purposeful use of lists, graphics, and patient friendly language. Of note, while the average rating was adequate, there were webpages that were not created for a general audience to utilize. For example, when searching “What is a genetic counselor?” one of the top webpage’s links to the Genetic Counseling Graduate Program in Cincinnati (“Genetic Counseling Graduate Program,” n.d.). While this page may be helpful for individuals looking to learn more about becoming a genetic counselor, the information that it conveys is less appropriate for the general population to learn about genetic counseling. Additionally, the webpages on genetic testing and genetic counseling from NHGRI included recorded narrations of their written material (“Genetic Counseling,” 2022; “Genetic Testing,” 2022). While these webpages were rated as adequate, the addition of recorded material may increase the accessibility of the information for the audience by providing another mode of consuming the information.

A comparison of the FK, SMOG, and SAM scores across the sponsor types revealed that webpages from professional organizations had the lowest average FK and SMOG scores among all sponsor types. A webpage sponsored by the American Academy of Family Physicians, titled “Genetic Testing: What you should know”, had the lowest FK grade level at 5.4 and the lowest SMOG level at 9.5 (“Genetic Testing: What You Should Know,” 2020). The highest averages among the sponsors were pages from government groups including the CDC and the National Human Genome Research Institute. In instances when patients have been asked to determine what factors they consider when looking for a webpage to gather health information, reliability was a top priority. 72% of respondents in a 2002 study of internet health information noted that they found webpages sponsored by a “medical society” to be more reliable than other sources (Diaz et

al., 2002). Knowing that patients find sites sponsored by medical societies to be most reliable, it is reassuring to know that these webpages were most likely to be appropriate for patient usage from a readability and suitability standpoint. Although the reported averages for the SMOG and FK scores in each sponsor type had some notable ranges in scores, they were not statistically significant. This indicates that there is not a difference between the FK and SMOG scores across the sponsor types and none of the sponsor groups were better or worse at creating readable materials.

Overall, the majority of webpages had reading levels that were above the recommended sixth to eighth grade level. Additionally, it was noted that the webpages were adequate for the population. While this may mean that the webpages do have some features that are appropriate, it also means that webpages are missing key components that make them usable by all audiences, including graphics, informational content, logical flow, and proper organization of content. This presents a problem for patients accessing these sites to learn more about genetic counseling or genetic testing prior to their appointment. If patients are accessing these webpages that they cannot completely comprehend, or that they cannot navigate to find appropriate information, they may not be able to properly inform themselves prior to their appointment. Genetic counselors have noted that patients may not follow through with their referral because of a lack of knowledge about genetic counseling and genetic testing (Rolnick, 2011) Poor health literacy and unsuitable information can lead to patients skipping specialist appointments, misusing medications, and not following through with recommendations from providers such as preventative screenings (Kutner, 2006; Weiss, 2003). Misunderstandings of information presented on the internet can lead to even further concerns for patients properly and actively participating in their own health care.

It has been suggested as well that limited health literacy and inaccessible healthcare materials can lead to a lack of informed consent (Graham & Brookey, 2008). In the genetic counseling and genetic testing space especially, concerns of informed consent are especially important. Overall, the high reading levels and missing accessibility pieces of the webpages studies in this project highlights the greater widespread public health concern that is low health literacy and inappropriate information being conveyed to patients.

2.4.1 Limitations

This study has several limitations. Because there have been limited studies on readability and suitability of webpages accessed by patients, specifically ones generated from search engine queries, there was no clear framework for developing methods to complete this analysis. Rather pieces from various web-based readability and suitability studies had to be adapted and brought together. This study also relied only on one search engine. Several previous frameworks from similar studies utilized a variety of search engines to create their webpage lists. Although this limited the possible variety of results, utilizing only one search engine allowed for further exploration into the top ranked webpages of each search. Similarly, the website ranking from a Google search can change based on the date as well as previous search history. Although this was controlled for by recording all webpages on the same day while using an Incognito browsing window, this did not allow for collection to be done over time. Additionally, assessing reading levels can be difficult for written information regarding genetics. Because genetics uses complex terms, which are often long and have many syllables, the reading levels may be inflated for an entire document based on only a few words or sentences. A significant limitation of this study, as well as other studies surrounding health literacy, is the lack of updated data to show the average

reading level within the United States. The most recent analysis was conducted in 2003, and without continued updating, there is possibility that this average has shifted in the last 20 years. Finally, there were two main limitations with the SAM tool. First, this tool is subjective in nature. Although raters are all using the same scoring rubric, each rater may have a different understanding of what each factor is looking for, or how that is displayed within a webpage. This can lead to discrepant scores overall. Another major limitation of the SAM tool is that it was not originally created with the intent to use on web-based materials. The tool considers factors such as paper quality and cover art when these factors are not assessable for a web resource (Doak, 1996a).

2.4.2 Future Research

The data and conclusions generated from this analysis continue to support the widespread concern of information being inappropriate for patients and leading to poor outcomes in a patient's health journey. To the study team's knowledge, this study was the first of its kind in the field of genetic counseling and genetic testing to take a broad look at the information patients may find on the internet when trying to learn more about a genetic counseling referral. With that being said, this research also highlights the need for future studies that take a deeper look at how genetic counseling and genetic testing is conveyed on the internet. This study did not discuss accuracy of information. Inaccurate information can pose problems for patients on top of their ability to comprehend and navigate the information. A future project could look into the accuracy of genetic information presented in similar internet question searches. Additionally, further research into the outcomes of patients that search for this information and utilize it in decision making regarding genetic counseling and genetic testing. Continuing to understand how patients use the information they learn before meeting with genetic counselors can help genetic counselors better tailor

counseling sessions. Finally, future research into ways to make online information more suitable to patients is necessary to combat the ongoing concerns.

2.5 Conclusions

Low health literacy is a public health concern across many healthcare fields, including genetics. To combat this, healthcare materials should be written at appropriate reading levels, as well as be constructed in a way that is accessible and appropriate for a general audience. A majority of the webpages accessed during this project were found to have reading grade levels higher than the recommended 6th to 8th grade level. Similarly, many webpages are only noted to be adequately suitable for the general population to utilize. These conclusions match with data from previous studies done on the readability and suitability of webpages across other disciplines. Because this is the first study to be conducted on information as it relates to genetic testing and genetic counseling, there is a need for continued exploration. Patients must be able to adequately read, comprehend, and move through web-based information as they make decisions for their genetic health care. Developers and sponsors of webpages with this information should continue to consider the appropriateness of their webpages.

3.0 Research Significance to Genetic Counseling and Public Health

To date, there has been no investigation into the webpages that patients can utilize to gain information about genetic counseling and genetic testing. Moreover, there has not been an understanding of if the information accessed by patients is written at a level they can comprehend, and if it is suitable for them as well. The project presented here is a high-level evaluation of what these metrics show for a selection of easily accessible information. The baseline knowledge presented here is necessary to establish that continued work must be done to ensure information about genetic counseling and genetic testing is created with patient access in mind.

Previous research indicates that health materials and resources are not written appropriately for the general public to access (Safeer, 2005). The study conducted concludes that this discrepancy is also seen in the webpages related to genetic counseling and genetic testing. With the understanding that poor health literacy and inappropriate health resources can lead to mismanagement of medical conditions and poorer overall health outcomes, it is not hard to draw conclusions as to how the inequities of the information about genetic counseling and genetic testing that is presented can lead to misunderstandings for patients. However, efforts are in place currently within the United States to organize more suitable resources for patients, and these efforts should extend to the genetic counseling space.

The United States has a plan in place, as part of Healthy People 2030, to improve health literacy across the nation ("Health Literacy in Healthy People 2030,"). The National Action Plan to Improve Health Literacy has a total of seven goals in place to improve national health literacy (*National Action Plan to Improve Health Literacy*, 2010). The goals include: "creating and implementing health information that is clear and accessible, promoting health care system change

that improves health information and decision making, incorporating health and science curriculum at appropriate levels in all education systems, supporting and expanding adult education offerings for health services, building partnerships, increasing research and development, and increasing the dissemination and utilization of health literacy interventions” (*National Action Plan to Improve Health Literacy*, 2010). Understanding the readability of webpages related to genetic counseling and genetic testing promotes the first goal of the National Action Plan to Improve Health Literacy. By determining that the webpages in this study were not written at a grade level appropriate for the general population, groups such as the National Society of Genetic Counselors, the CDC, and many health care systems can begin revising their webpages to include material that is more accessible to patients from a readability standpoint.

Not only does this research impact public health, but it also has an impact on the genetic counseling profession. Patients are referred to genetic counseling services, often with little understanding of what genetic counseling is or what an appointment entails (Maio et al., 2013). Many genetic counselors have cited that this lack of knowledge contributes to patients having poor follow through with appointments (Rolnick, 2011). Faced with limited information about genetic counseling, patients may turn to the internet to learn more prior to their appointment. While the internet can be a valuable resource for gaining valuable information, it can also cause increased misunderstandings and misconceptions for patients. This study shows that prominent webpages about genetic counseling and genetic testing are inaccessible to patients. The average patient may be unable to fully comprehend the information presented on these webpages because the reading level is well above their abilities. Similarly, the webpages are missing key factors to make them superiorly suitable, such as appropriate graphics, common vocabulary, and style choices that make the information easier to move through. When presented with this inaccessibility, patients may

find it difficult to understand the importance of genetic counseling or the value that genetic testing can provide to their health care.

Genetic counselors should be aware of these disparities in order to better counsel patients. First, genetic counselors that are involved in the creation of web-based resources should take suitability and readability into account. Genetic counselors in this capacity should consider using plain language when appropriate and organizing material in an appropriate manner. Presenting genetic information in a lower reading level can be difficult because of the complex words and ideas that are necessary to talk about genetics. However, being sure to follow up any difficult or technical words and phrases with clear, concise explanations is one way to take readability and suitability into account. Additionally, genetic counselors should be aware that not all of the information presented in webpages about genetic counseling and genetic testing is the most appropriate for a patient population. For example, the webpage focused on genetic counseling graduate programming addresses the pathway to becoming a genetic counselor but provides limited information to patients about what a genetic counselor is or what they do. In this case, genetic counselors who are able to provide resources to patients before an appointment, or to commonly referring providers, may consider creating a list of appropriate web resources. Another consideration for genetic counselors is that the confusion created by the high reading levels of these webpages may cause patients to come into appointments with misconceptions about genetic counseling, or they may not follow through with their appointment at all. Genetic counselors will need to be prepared to address these misconceptions through their counseling. Finally, in some cases, the material for web-based resources is created by genetic counselors. Should a genetic counselor be tasked with developing a resource, it is necessary that they are aware of the importance of readability and suitability in order to create content that is appropriate.

The conclusions generated from this study are relevant to both public health and genetic counseling practice because they establish that the issue of web-based resources being inaccessible and inequitable for patients transcends different aspects of information regarding genetic testing and genetic counseling. By establishing these relationships, genetics professionals can adjust their own counseling or resource lists appropriately. Similarly, this data provides a baseline argument for the importance of the efforts being conducted by Healthy People 2030 to increase health literacy. This data presents a case for considering organizational health literacy and ways that groups sponsoring webpages can tailor their information to be more suitable for, and readable by, the average patient.

4.0 MPH ESSAY: Organizational health literacy and creating suitable examples for genetic counseling and genetic testing

4.1 Background

The Healthy People initiative was started in 1979 in response to a report from the Surgeon General around health promotion and disease prevention. Since there have been five iterations of the initiative, including Healthy People 2030 ("Healthy People 2030 Framework, "). Each iteration of Healthy People aims to build on the foundation of the previous goals and address the most important public health priorities. Healthy People 2030 has a mission "to promote, strengthen, and evaluate the nation's efforts to improve the health and wellbeing of all people ("Healthy People 2030 Framework, "). In order to achieve this mission, Healthy People 2030 has laid out a set of five specific goals. One of these goals surrounds eliminating health disparities and attaining health literacy ("Healthy People 2030 Framework, ").

As a part of this initiative, Healthy People 2030 redefined health literacy in terms of "personal health literacy" and "organizational health literacy." Personal health literacy is the traditional understanding of health literacy. This includes an individual's "ability to find, understand, and use information and services" in order to make well-informed health decisions and take action related to their own or others health ("Health Literacy in Healthy People 2030, "). Healthy People 2030 defines organizational health literacy as follows: "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 ("Health Literacy in Healthy People 2030, ")." In moving the definition of health literacy away from being the

responsibility of an individual, Healthy People 2030 is recognizing that the groups who sponsor and disseminate health information are also responsible for promoting health literacy. Similarly, providing a definition of organizational health literacy places emphasis on the need for sponsors of healthcare materials to equitably share their information in a way that fully addresses the scope of health literacy within the United States.

The Suitability Assessment of Materials (SAM) was created by Doak, Doak, Miller, and Wilder in 1994 as part of a Johns Hopkins School of Medicine Study on nutritional education in African Americans (Doak, 1996a). The SAM was developed out of a need for health care providers to evaluate their healthcare instruction systematically and quickly for different audiences. SAM has been applied to determine suitability of video and audio as well. SAM provides scores of superior, adequate, or not suitable based on a set of 6 criteria: content, literacy demand, graphics, layout, and typography, learning stimulation and motivation, and cultural appropriateness. (Doak, 1996) The SAM framework addresses the aspects of accessibility of materials that traditional reading ease or appropriateness measures do not account for. By providing a numerical rating to the categories listed above, healthcare providers and other professionals can assess written documents both in print and online (Doak, 1996a).

The aim of this project is to understand organizational health literacy, and to provide examples of ways in which this can be achieved, regarding information about genetic counseling and genetic testing to be published online. The examples will take into account the principles of the Suitability Assessment of Materials (SAM). SAM aims to rate materials based on categories of content, literacy demand, graphics, layout and typography, learning motivation, and cultural appropriateness (Doak, 1996a). Keeping these factors in mind will allow for the creation of examples and practices that aim to be “superior” on the SAM scale. The examples will also utilize

the data generated from SAM ratings of a set of 17 webpages focused on genetic counseling and genetic testing that were generated from an internet question search. This project is by no means an all-inclusive guide to creating resources that are equitable in terms of health literacy. Organizations that disseminate this information can utilize the examples presented here to begin building web-based resources that patients can gather more appropriate information from in the future.

4.1.1 Specific Aims

The specific aims for this study were as follows:

1. To determine practices for organizations to meet the Healthy People 2023 definition of organizational literacy and equitably provide information to the public regarding genetic counseling and genetic testing using the SAM superior factors.
2. To present examples of suitable and appropriate information about genetic counseling and genetic testing based on the SAM superior factors.

4.2 Methods

The webpages listed in Appendix B and analyzed in Appendix C were generated through Incognito Google searches of four different questions. These questions included “what is a genetic counselor”, “what is genetic testing”, “what happens at a genetic counseling appointment”, and “why do I need genetic testing.” These questions were determined by the authors of this study to be common questions searched by patients referred for genetic counseling and genetic testing. The

webpage list was generated on March 22, 2022. Each webpage was evaluated using the SAM criteria by two primary raters. A third rater was brought in to evaluate webpages with discrepant scores. A score sheet was used by each rater to maintain consistency. The score sheet used can be found in chapter 4 of “Teaching Patients with Low Literacy Skills” which is accessible via The Harvard T.H. Chan School of Public Health: Health Literacy Studies Web Site (Doak, 1996b). To evaluate the criteria of readability, the Flesh Kincaid (FK) score was used for all websites. In order to prevent webpages undergoing updates during evaluation, all SAM scores were determined during October 2022, and screenshots were taken in case reanalysis was necessary. Reported SAM rating for each webpage was assigned based on majority rating, as shown in Appendix C.

In order to create a set of practices for organizations to better address information about genetic counseling and genetic testing, the SAM tool was used as a framework. There are six categories of SAM: content, literacy demand, graphics, layout and topography, learning stimulation and motivation, and cultural appropriateness (Doak, 1996a). Each of the categories has a list of factors, totaling twenty-two. Specifically, there are qualifications within each factor that make a material superior. A superior material must score between 70% and 100% rating. The qualifications to be superior in all categories of SAM are listed in the table below (Doak, 1996a). Examples were also generated based on the webpages listed in Appendix C that were rated as superior either overall or in a specific category. The superior category webpages shown in Appendix C provided models for how to organize and address the complex information involved in creating resources for genetic counseling and genetic testing.

Table 12. SAM superior qualities (Doak, 1996a)

Factor (Category Number)	Superior Qualities
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Purpose is evident (I)	Purpose is explicitly stated in title, or cover illustration, or introduction.
Content about behaviors (I)	Thrust of the material is application of knowledge/skills aimed at desirable reader behavior rather than non-behavior facts.
Scope is limited (I)	Scope is limited to essential information directly related to the purpose. Experience shows it can be learned in time allowed.
Summary or review is included (I)	A summary is included and retells the key messages in different words and examples
Reading grade level (II)	5 th grade level or lower (5 years of schooling level)
Writing style, active voice (II)	1. Mostly conversational style and active voice <u>AND</u> 2. Simple sentences are used extensively; few sentences contain embedded information
Vocabulary uses common words (II)	1. Common words are used nearly all of the time <u>AND</u> 2. Technical, concept, category, value judgement (CCVJ) words are explained by examples <u>AND</u> 3. Imagery words are used as appropriate for content
Context is given first (II)	Consistently provides context before presenting new information
Learning aids via “road signs”, subtitles and captions (II)	Nearly all topics are preceded by an advance organizer (a statement that tells what is coming next)
Cover graphic shows purpose (III)	The cover graphic is friendly, attracts attention, clearly portrays the purpose of the material to the intended audience
Types of graphics (III)	1. Simple, adult appropriate, line drawing/sketches are used <u>AND</u> 2. Illustrations are likely to be familiar to the viewers.
Relevance of illustrations (III)	Illustrations present key messages visually so the reader/viewer can grasp the key ideas from the illustrations alone. No distractions.
Lists and tables are explained (III)	Step-by-step directions, with an example, are provided that will build comprehension and self-efficacy.
Captions used for graphics (III)	Explanatory captions with all or nearly all illustrations and graphics.
Layout factors (IV)	At least five of the follow 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 non-gloss or low-gloss surface.
Typography (IV)	1. Text type is in uppercase and lowercase serif (best) or sans-serif <u>AND</u> 2. Type size is at least 12-point font <u>AND</u> 3. Typographic cues (bold, size, color) emphasize key points <u>AND</u> 4. No all caps for long headers or running text

Subheads (“chunking”) used (IV)	1. Lists are grouped under descriptive subheadings or “chunks” <u>AND</u> 2. No more than five items are presented without a subheading
Interaction used (V)	Problems or questions presented for reader responses
Behaviors are modeled and specific (V)	Instruction models specific behaviors or skills
Motivation, self-efficacy (V)	Complex topics are subdivided into small parts so that readers may experience small successes in understanding or problem solving, leading to self-efficacy
Match in logic, language, experience (LLE) (VI)	Central concepts/ideas of the material appear to be culturally similar to the LLE of the target audience
Cultural image and examples (VI)	Images and examples present the culture in positive ways

This table contains direct quotes from the SAM tool (Doak, 1996a).

4.3 Suggested Practices and Examples

The creation of suitable and appropriate web-based resources is no easy task. By utilizing the SAM framework for superior materials, organizations can begin to address the task of implementing organizational health literacy and increasing the accessibility of their webpages. Because this is not a complete guide for creating resources, not every SAM factor will have an example, rather emphasis will be placed on creating at least one example from each SAM category. A summary of the examples presented can be found in Table 13.

The first SAM category, content, focuses on identifying the purpose and scope of the material (Doak, 1996a). One way an organization can achieve this goal is by creating titles that explicitly describe the main focus of the webpage. For example, webpages such as “What to expect when meeting with a genetic counselor” or “Making smart decisions about genetic testing” clearly describe the purpose of the resource (“Making Smart Decisions About Genetic Testing,” 2015;

"What to Expect When Meeting With a Genetic Counselor," 2021). Based on these titles, a reader would be able to gather enough context to understand the main purpose of the resource and decide if it may have the information they are seeking. Additionally, organizations should be sure the content of the webpage stays within the scope of the purpose. This includes removing extraneous information that does not directly contribute to a reader's knowledge about the topic of the page. Organizations can add summary sections within their resources to provide a high-level overview of what the resource was focused on. For example, a webpage that was focused on what a genetic counselor is may summarize the information in a simple paragraph at the end that has the main points of what a genetic does, as shown in the example sentences from the NSGC "About Genetic Counselors" page in Table 13 ("About Genetic Counselors," n.d.).

The second category for SAM is focused on literacy demand and addresses the significant issue of reading level within resources (Doak, 1996a). Of the webpages listed in Appendix C, none of the webpages scored a superior rating in terms of reading level. This means that all the webpages had reading levels that were greater than fifth grade. A challenge for organizations looking to increase health literacy based on reading level is the amount of complex or technical terms that are used in information about genetic counseling and genetic testing. However, one way that lower reading levels can be established is by using common vocabulary where applicable and limiting the number of complex, or multi-syllable, words within sentences. Similarly, when a technical term must be used, providing context to that term with further explanation is necessary. An example of this technique, with reported FK reading level, is shown in Table 13. Additionally, the use of readability calculators and toolkits, such as Readable.com and the PRISM Toolkit, provide further support for creating readable webpages (Ridpath JR, 2007).

SAM category three focuses on graphics and other figures (Doak, 1996a). Organizations should consider ways to utilize simple, clear illustrations and figures throughout their resources. For resources about genetic testing, this might include a simple graphic of the testing process that has clear steps outlined. Simple and clear cover graphics, as outlined by the superior qualities enhancing suitability of webpages. In the analysis of the webpages shown in Appendix B and further described in Appendix C, it is clear that graphics were often not included in webpages or were poorly done (scoring a 0 or 1 on the SAM scale). Increasing the use of graphics where appropriate should also be considered a best practice for organizations to achieve greater health literacy. Additionally, if webpages choose to incorporate graphics and images, they must be accompanied by captions that describe the image and any necessary information to understand the image.

Category four centers around the overall layout and typography of the resource (Doak, 1996a). This includes factors such as the organization of information, the size and style of font, the use of white space, and coloring and shading. To create a superiorly suitable resource with these factors in mind, organizations should consider implementing a logical flow to their information. This could include beginning with broad information and moving to more specific information. It could also include organizing information into subheadings, or “chunks,” to help readers follow along more clearly. Consideration should also be taken to make sure the webpage is accessible from a visual standpoint. This means that the use of colors and shading should only be done when appropriate and should not distract from the overall content of the resource. For example, headings of each section could be bold or a different color to signal to readers that they are moving to a new section. When items like lists or subheadings are presented, five or fewer points should be listed underneath. An example of this is shown in Table 13. Additionally,

consideration should be given to the amount of white, or blank, space left on a webpage. Leaving adequate white space to the sides of, and between, chunks of text or figures can give readers a place to rest their eyes and helps them to keep focus on the important information.

SAM's fifth category focuses on stimulating learning and motivating the reader (Doak, 1996a). This can be done through a variety of methods. One way presented in the superior SAM factors is to use specific instructions or steps to motivate the reader. Modeling the desired behavior for the audience allows them to prepare for possible scenarios and gives them a framework to build from. For example, within a webpage about what to expect at a genetic counseling appointment, there may be section pertaining to preparing for an appointment. This section could include information about collecting family history prior to talking about it with the genetic counselor. These steps would be easy to follow instructions that would engage the reader in collecting this information for themselves and motivate them to be prepared prior to their appointment. The example shown in Table 13 outlines a few questions that patients may want to ask their family members. This puts the emphasis on important information that is needed in a family history, while engaging the reader in determining what would be best to ask. By providing patients with an outline for acting on certain behaviors, patients may be more informed of what is expected not only from a genetic counselor during a session, but also what they as patients are expected to contribute to the session as well.

The final SAM category is centered around cultural appropriateness (Doak, 1996a). In order to be superior SAM suggests using language that is culturally appropriate for the audience in terms of experience and background. Similarly, SAM proposes that the target audience should be presented in a positive way through examples and images. In order to meet these suggestions, the organizations creating these webpages must first understand their target population. For the

purposes of these suggestions, the general U.S. population will be used as the target. Based on census information, the U.S. population is made up of individuals of many different race and ethnic backgrounds, as well as various education and employment backgrounds (*Quick Facts United States*, 2022). Additionally, the United States population has individuals of various sexual and gender orientations (Brown, 2022; *Quick Facts United States*, 2022). Organizations looking to present information equitably to the United States population should keep all of those factors in mind. An example of this could be using gender-neutral language where appropriate in a document, such as replacing “mother and father” with “parents.” Another consideration is in the images that a resource uses. Because there are people of different backgrounds within the United States, it is important to positively represent them in the images used. This could include photos or depictions of people with different skin tones, different religious backgrounds, and different gender or sexual identities. When considering the experiences of the target audience, it is important to remember that many individuals in the United States have not heard of genetic counselors, or have limited understanding of genetic counseling and genetic testing (Maio et al., 2013). Remembering that most individuals lack this experience is important to conveying the right level of appropriate information.

Table 13. Examples of superior practices for information related to genetic counseling and genetic testing

Factor (Category Number)	Superior Example
Purpose is evident (I)	<p><u>Examples from Webpage Analysis:</u></p> <ul style="list-style-type: none"> - “What to expect when meeting with a genetic counselor” (“What to Expect When Meeting With a Genetic Counselor,” 2021) - “Making smart decisions about genetic testing” (“Making Smart Decisions About Genetic Testing,” 2015)

Summary or review is included (I)

Author suggested example: A genetic counselor is a healthcare provider who supports patients in learning more information about inherited conditions and diseases. Genetic counselors also help patients understand their family history and understand genetic testing. [Adapted from the National Society of Genetic Counselors ("About Genetic Counselors," n.d.)]

Reading grade level (II) + Vocabulary uses common words (II)

Author suggested example: Genes are the instructions for our body. These instructions help us grow and develop. Changes in these genes, called variants, make us all different. (FK grade: 5.0)

Example from Webpage Analysis:

- <https://www.cancer.net/navigating-cancer-care/cancer-basics/genetics/what-expect-when-meeting-genetic-counselor> ("What to Expect When Meeting With a Genetic Counselor," 2021)
- <https://kidshealth.org/en/parents/genetics.html> (Anzilotti, 2021b)
- <https://www.choosingwisely.org/patient-resources/making-smart-decisions-about-genetic-testing/> ("Making Smart Decisions About Genetic Testing," 2015)

Additional Resources:

- Readability calculator: <https://readable.com/>
- PRISM Readability Toolkit: https://www.nhlbi.nih.gov/files/docs/ghchs_readability_toolkit.pdf (Ridpath JR, 2007)
- Plain Language Action and Information Network: <https://www.plainlanguage.gov/>

Cover graphic shows purpose (III) + Types of graphics (III)

A graphic showing the process for genetic testing within a resource focused on understanding genetic testing. Simple drawings that are easy to follow such as a basic line drawing of a DNA helix or a test tube.

Layout factors (IV)

- Leaving white space to the sides of and between chunks of text for readers to rest their eyes.
- Including bolding or shading of headings and titles that is not a distracting color.
- Implementing a logical flow of information that is easy to follow, such as starting with broad information and moving to more detailed information.
- Limiting popups or outside ads, when possible, to reduce distractions

Additional Resources:

- U.S. Department of Health and Human Services Office of Disease Prevention and Health Promotion Web Design Guide: https://health.gov/healthliteracyonline/2010/Web_Guide_Health_Lit_Online.pdf
- Digital.gov Guides and Resources: <https://digital.gov/resources/>

Typography (IV)

Utilizing fonts that are easy to read and have clear distinction between letters, such as serif fonts.

Common serif fonts:

- Times new roman (example text)
- Georgia (example text)
- Garamond (example text)
- Courier New (example text)

Subheads (“chunking”) used (IV)**Author suggested example:**

A genetic counselor can:

- Review your family history
- Discuss your risk for genetic conditions
- Give you information about genetic testing

Example from Webpage Analysis

- https://www.cdc.gov/genomics/gtesting/genetic_counseling.htm ("Genetic Counseling," 2020)
- <https://www.nsgc.org/About/About-Genetic-Counselors> ("About Genetic Counselors," n.d.)
- <https://www.breastcancer.org/genetic-testing/what-to-expect> ("How To Prepare for Genetic Counseling," 2020)

Behaviors are modeled and specific (V)

Author suggested example: It is important to gather family history information before your appointment. You might consider asking your family members if they have ever been diagnosed with a genetic condition, or if they have ever had genetic testing. You might also ask if any family members have any illnesses or other health concerns.

Example from Webpage Analysis:

- <https://www.choosingwisely.org/patient-resources/making-smart-decisions-about-genetic-testing/> ("Making Smart Decisions About Genetic Testing," 2015)
- https://www.cdc.gov/genomics/gtesting/genetic_testing.htm ("Genetic Testing," 2020b)

Match in logic, language, experience (VI) + Cultural image and examples (VI)

For the general United States Population, this could include:

- Graphics and images that display individuals of many ethnicities, races, and background
- Language that is gender neutral where appropriate
- Recognizing that most individuals have not had experience with genetic services or professionals before

Additional Resources:

- American Psychological Association Language Guide: <https://www.apa.org/about/apa/equity-diversity-inclusion/language-guidelines>
- U.S. Department of Health and Human Services Think Cultural Health Resources: <https://thinkculturalhealth.hhs.gov/resources/library>

4.4 Conclusions and Implications

As groups that sponsor webpages become more organizationally health literate, they will contribute to the overarching efforts of Healthy People 2030 to increase health literacy at both personal and system wide levels. Low health literacy has been shown to have wide reaching implications on the health and wellbeing of individuals. Individuals with low health literacy are more likely to have poor health outcomes leading to hospitalizations, misuse of medications, and poor follow through with medical appointments (Kutner, 2006; Schillinger, 2020; Weiss, 2003). In the field of genetic counseling, many genetic counselors have cited the lack of information about genetic counseling and genetic testing as a reason why patients are less likely to follow through with their referrals (Rolnick, 2011). The implications of this project support an argument that there is a lack of appropriately suited knowledge patients can gather before an appointment. Being unable to find information ultimately leads to patients making misinformed decisions that have great impact on their healthcare and management, such as not attending an appointment or misunderstanding the possible results of genetic testing.

In order to achieve organizational health literacy, the sponsors and other organizations that contribute to webpages about genetic counseling and genetic testing need to consider many different factors. Organizational health literacy relies on information being presented to readers in an equitable fashion that makes it clear and understandable so that they can use it toward making health decisions. One way to accomplish this task is to create webpages that are more suitable for the general public. Utilizing the SAM framework and focusing on the suggestions in each category for a superior material, a set of best practices and examples was extrapolated. Best practices include items like keeping content focused and appropriate, having a clear purpose, using culturally positive and easy to follow graphics and images, using a logical layout and organization,

and keeping reading levels low. The examples provided in this project give a foundation for organizations to update current resources or create new ones that align more closely with the goals of organizational health literacy.

4.4.1 Limitations

The webpages analyzed as a part of this project were limited to a small subset of available resources. This small sample was taken at a single point in time and represents only a portion of information that patients can gather through the internet. Additionally, the examples provided in this project were created by the author, and do not represent all possible options for how to use the SAM framework to create suitable resources. The FK grade level was used to analyze the reading level of the webpages and examples presented in this project. FK grade level scores have been shown to be less reliable in the medical and science context, despite its widespread availability as a rating scale (Jindal & MacDermid, 2017). Finally, there has been limited previous work surrounding organizational health literacy. This concept was presented as part of Healthy People 2030 and is part of an ongoing research initiative. There has not yet been clear data to show if organizational health literacy efforts contribute to increased health literacy in general.

Appendix A IRB Exemption Letter



Office of Research Protections
Human Research Protection Office

Hieber Building, Suite 401
3500 Fifth Avenue
Pittsburgh, PA 15213
412-383-1480
www.hrpo.pitt.edu

MEMORANDUM

TO: Madalyn Charnego

FROM: Human Research Protection (HRP)

DATE: January 25, 2023

SUBJECT: IRB# 2301005: Analyzing the Readability and Suitability of Webpages Related to Genetic Counseling and Genetic Testing

The above-referenced research study has been reviewed by the University of Pittsburgh Institutional Review Board. Based on the information provided to the IRB, this project includes no involvement of human subjects, according to the federal regulations [45 CFR 46.102(e)]. That is, the investigator conducting research will not obtain data through intervention or interaction with the individual, or will not obtain identifiable private information. Should that situation change, the investigator must notify the IRB immediately.

Appendix B List of Webpages

- What is a genetic counselor?
 - https://www.cdc.gov/genomics/gtesting/genetic_counseling.htm
 - <https://www.genome.gov/genetics-glossary/Genetic-Counseling>
 - <https://www.cincinnatichildrens.org/education/clinical/student-grad/genetic-counseling/prospective-students>
 - <https://www.nsgc.org/About/About-Genetic-Counselors>
 - <https://www.cancer.net/navigating-cancer-care/cancer-basics/genetics/what-expect-when-meeting-genetic-counselor>

- What happens at a genetic counseling appointment?
 - <https://medlineplus.gov/genetics/understanding/consult/expectations/>
 - <https://www.cancer.net/navigating-cancer-care/cancer-basics/genetics/what-expect-when-meeting-genetic-counselor>
 - <https://kidshealth.org/en/parents/genetic-counseling.html>
 - <https://uihc.org/health-topics/frequently-asked-questions-about-genetic-counseling-and-testing>
 - <https://www.breastcancer.org/genetic-testing/what-to-expect>

- What is genetic testing?
 - <https://medlineplus.gov/genetics/understanding/testing/genetic-testing/>
 - https://www.cdc.gov/genomics/gtesting/genetic_testing.htm
 - <https://www.genome.gov/genetics-glossary/Genetic-Testing>

- <https://www.mayoclinic.org/tests-procedures/genetic-testing/about/pac-20384827>
- <https://kidshealth.org/en/parents/genetics.html>
- Why do I need genetic testing?
 - https://www.cdc.gov/genomics/gtesting/genetic_testing.htm
 - <https://medlineplus.gov/genetics/understanding/testing/benefits/>
 - <https://www.mayoclinic.org/tests-procedures/genetic-testing/about/pac-20384827>
 - <https://www.choosingwisely.org/patient-resources/making-smart-decisions-about-genetic-testing/>
 - <https://familydoctor.org/genetic-testing-what-you-should-know/>

Appendix C SAM Ratings

Table 14. SAM ratings part 1

	Genetic Counseling- CDC	Genetic Counseling- CDC	Genetic Counseling- NHGRI	Genetic Counseling- NHGRI	Genetic Counseling Graduate Program	Genetic Counseling Graduate Program
Reviewer	A	B	A	B	A	B
Purpose is Evident	2	2	2	2	2	1
Content about behaviors	1	1	1	0	1	1
Scope is limited	2	1	2	2	2	2
Summary or review included	0	1	0	1	0	0
Reading grade level	0	0	0	0	0	0
Writing style, active voice	1	2	2	1	1	1
Vocabulary uses common words	1	1	1	1	2	1
Context is given first	1	2	2	2	2	2
Learning aids via road signs, subtitles, captions	2	2	0	1	2	2
Cover graphic shows purpose	N/A	1	1	2	N/A	2
Types of graphics	N/A	1	2	2	N/A	1
Relevance of illustrations	0	1	2	1	N/A	1
Lists and tables explained	N/A	N/A	N/A	N/A	N/A	N/A
Captions used for graphics	N/A	N/A	N/A	N/A	N/A	N/A
Layout factors	2	1	1	1	1	1
Typography	2	2	1	2	2	2
Subheads "chunking" used	2	2	0	N/A	2	2
Interaction used	0	0	0	0	0	1
Behaviors are modeled and specific	N/A	1	N/A	1	N/A	1
Motivation, self-efficacy	2	2	2	2	2	2
Match in logic, language, experience	1	1	1	1	0	2
Cultural image and examples	1	1	N/A	1	N/A	2
TOTAL	20	25	20	23	19	27
NUMBER N/A	5	2	4	3	7	2
#N/A x2	10	4	8	6	14	4
44 - N/Ax2 (Revised maximum score)	34	40	36	38	30	40
TOTAL / Revised Max	0.58823529	0.625	0.55555556	0.60526316	0.63333333	0.675
Interpretation	Adequate	Adequate	Adequate	Adequate	Adequate	Adequate

Table 15. SAM ratings part 2

	About Genetic Counselors	About Genetic Counselors	What to expect when...	What to expect when...	What happens during...	What happens during...
Reviewer	A	B	A	B	A	B
Purpose is Evident	1	2	2	2	2	2
Content about behaviors	0	0	1	2	1	1
Scope is limited	2	2	1	2	2	2
Summary or review included	0	0	0	0	0	0
Reading grade level	0	0	1	1	0	0
Writing style, active voice	1	2	2	1	2	1
Vocabulary uses common words	1	1	2	1	2	1
Context is given first	0	1	1	2	1	1
Learning aids via road signs, subtitles, captions	0	1	1	2	1	2
Cover graphic shows purpose	N/A	2	N/A	1	N/A	0
Types of graphics	N/A	1	N/A	1	N/A	0
Relevance of illustrations	N/A	1	N/A	1	N/A	0
Lists and tables explained	N/A	N/A	N/A	N/A	N/A	N/A
Captions used for graphics	N/A	N/A	N/A	N/A	N/A	N/A
Layout factors	1	1	2	2	1	1
Typography	2	2	2	2	2	1
Subheads "chunking" used	2	0	2	2	2	2
Interaction used	0	1	1	1	0	0
Behaviors are modeled and specific	N/A	1	N/A	1	N/A	1
Motivation, self-efficacy	1	1	2	2	1	1
Match in logic, language, experience	1	1	2	2	1	2
Cultural image and examples	N/A	1	N/A	1	N/A	1
TOTAL	12	21	22	29	18	19
NUMBER N/A	7	2	7	2	7	2
#N/A x2	14	4	14	4	14	4
44 - N/Ax2	30	40	30	40	30	40
(Revised maximum score)						
TOTAL / Revised Max	0.4	0.525	0.73333333	0.725	0.6	0.475
Interpretation	Adequate	Adequate	Superior	Superior	Adequate	Adequate

Table 16. SAM ratings part 3

	Genetic Counseling (For Parents)	Genetic Counseling (For Parents)	Frequently asked questions...	Frequently asked questions...	How to prepare for genetic counseling	How to prepare for genetic counseling
Reviewer	A	B	A	B	A	B
Purpose is Evident	1	2	2	2	2	2
Content about behaviors	0	2	0	2	2	2
Scope is limited	1	2	2	2	1	2
Summary or review included	0	0	0	0	0	0
Reading grade level	0	1	0	0	0	0
Writing style, active voice	2	2	1	2	1	2
Vocabulary uses common words	2	2	1	1	2	1
Context is given first	1	2	1	2	1	2
Learning aids via road signs, subtitles, captions	2	2	2	2	2	2
Cover graphic shows purpose	N/A	0	N/A	N/A	N/A	N/A
Types of graphics	N/A	0	N/A	N/A	N/A	N/A
Relevance of illustrations	N/A	0	N/A	0	N/A	0
Lists and tables explained	N/A	N/A	N/A	N/A	N/A	N/A
Captions used for graphics	N/A	N/A	N/A	N/A	N/A	N/A
Layout factors	2	2	2	1	1	1
Typography	2	2	2	2	2	2
Subheads "chunking" used	2	0	2	1	2	2
Interaction used	1	1	1	1	1	0
Behaviors are modeled and specific	N/A	1	N/A	1	N/A	1
Motivation, self-efficacy	2	2	1	2	1	1
Match in logic, language, experience	2	2	1	1	1	1
Cultural image and examples	N/A	1	N/A	1	N/A	1
TOTAL	20	26	18	23	19	22
NUMBER N/A	7	2	7	4	7	4
#N/A x2	14	4	14	8	14	8
44 - N/Ax2 (Revised maximum score)	30	40	30	36	30	36

TOTAL / Revised Max	0.66666667	0.65	0.6	0.63888889	0.63333333	0.61111111
Interpretation	Adequate	Adequate	Adequate	Adequate	Adequate	Adequate

Table 17. SAM ratings part 4

	What is genetic testing	What is genetic testing	Genetic testing-CDC	Genetic testing-CDC	Genetic Testing-NHGRI	Genetic Testing-NHGRI
Reviewer	A	B	A	B	A	B
Purpose is Evident	2	2	2	2	1	1
Content about behaviors	0	0	1	1	1	1
Scope is limited	2	1	1	2	2	2
Summary or review included	0	0	1	1	1	2
Reading grade level	0	0	0	0	0	0
Writing style, active voice	1	0	1	2	2	1
Vocabulary uses common words	2	1	1	1	1	1
Context is given first	1	2	2	2	2	1
Learning aids via road signs, subtitles, captions	2	2	2	2	0	1
Cover graphic shows purpose	N/A	N/A	2	2	1	2
Types of graphics	N/A	N/A	1	1	2	1
Relevance of illustrations	N/A	N/A	1	1	2	1
Lists and tables explained	N/A	N/A	N/A	N/A	N/A	N/A
Captions used for graphics	N/A	N/A	N/A	N/A	N/A	N/A
Layout factors	1	1	2	2	1	1
Typography	2	2	2	2	1	2
Subheads "chunking" used	2	2	2	2	0	N/A
Interaction used	0	0	0	0	0	0
Behaviors are modeled and specific	N/A	1	N/A	2	N/A	1
Motivation, self-efficacy	1	2	1	2	1	2
Match in logic, language, experience	1	1	1	1	1	1
Cultural image and examples	N/A	N/A	N/A	1	N/A	1
TOTAL	17	17	23	29	19	22
NUMBER N/A	7	6	7	2	4	3
#N/A x2	14	12	14	4	8	6
44 - N/Ax2 (Revised maximum score)	30	32	30	40	36	38
TOTAL / Revised Max	0.56666667	0.53125	0.76666667	0.725	0.52777778	0.57894737
Interpretation	Adequate	Adequate	Superior	Superior	Adequate	Adequate

Table 18. SAM ratings part 5

	Genetic Testing- Mayo	Genetic Testing- Mayo	Genetic testing (for parents)	Genetic testing (for parents)
Reviewer	A	B	A	B
Purpose is Evident	2	1	1	2
Content about behaviors	2	1	1	1
Scope is limited	1	1	1	2
Summary or review included	1	0	1	0
Reading grade level	0	0	1	1
Writing style, active voice	1	1	2	2
Vocabulary uses common words	1	1	2	2
Context is given first	1	1	2	2
Learning aids via road signs, subtitles, captions	2	2	2	2
Cover graphic shows purpose	N/A	N/A	N/A	N/A
Types of graphics	N/A	N/A	N/A	N/A
Relevance of illustrations	N/A	0	0	0
Lists and tables explained	N/A	N/A	N/A	N/A
Captions used for graphics	N/A	N/A	N/A	N/A
Layout factors	1	2	2	2
Typography	2	2	2	2
Subheads "chunking" used	2	1	1	1
Interaction used	0	0	1	1
Behaviors are modeled and specific	N/A	1	1	1
Motivation, self-efficacy	2	2	2	2
Match in logic, language, experience	1	1	2	1
Cultural image and examples	N/A	N/A	N/A	N/A
TOTAL	19	17	24	24
NUMBER N/A	7	5	5	5
#N/A x2	14	10	10	10
44 - N/Ax2 (Revised maximum score)	30	34	34	34

TOTAL / Revised Max	0.63333333	0.5	0.70588235	0.70588235
Interpretation	Adequate	Adequate	Superior	Superior

Table 19. SAM ratings part 6

	What are the benefits of genetic testing	What are the benefits of genetic testing	What are the benefits of genetic testing
Reviewer	A	B	C
Purpose is Evident	2	2	2
Content about behaviors	0	1	2
Scope is limited	2	2	2
Summary or review included	0	0	N/A
Reading grade level	0	0	0
Writing style, active voice	2	2	2
Vocabulary uses common words	1	1	1
Context is given first	0	1	2
Learning aids via road signs, subtitles, captions	0	1	2
Cover graphic shows purpose	N/A	N/A	N/A
Types of graphics	N/A	N/A	N/A
Relevance of illustrations	0	0	0
Lists and tables explained	N/A	N/A	N/A
Captions used for graphics	N/A	N/A	N/A
Layout factors	0	1	2
Typography	1	2	2
Subheads "chunking" used	0	0	0
Interaction used	1	1	1
Behaviors are modeled and specific	1	1	1
Motivation, self-efficacy	0	2	2
Match in logic, language, experience	1	1	1
Cultural image and examples	N/A	N/A	N/A
TOTAL	11	18	22
NUMBER N/A	5	5	6
#N/A x2	10	10	12
44 - N/Ax2 (Revised maximum score)	34	34	32
TOTAL / Revised Max	0.32352941	0.52941176	0.6875
Interpretation	Not Suitable	Adequate	Adequate

Table 20. SAM ratings part 7

	Making smart decisions about genetic testing	Making smart decisions about genetic testing	Making smart decisions about genetic testing
Reviewer	A	B	C
Purpose is Evident	2	2	2
Content about behaviors	1	2	2
Scope is limited	1	1	2
Summary or review included	0	0	1
Reading grade level	1	1	1
Writing style, active voice	2	2	2
Vocabulary uses common words	1	2	2
Context is given first	1	2	1
Learning aids via road signs, subtitles, captions	1	2	1
Cover graphic shows purpose	N/A	N/A	N/A
Types of graphics	N/A	N/A	N/A
Relevance of illustrations	0	0	0
Lists and tables explained	N/A	N/A	N/A
Captions used for graphics	N/A	N/A	N/A
Layout factors	1	2	1
Typography	2	2	2
Subheads "chunking" used	2	2	2
Interaction used	1	1	0
Behaviors are modeled and specific	1	1	2
Motivation, self-efficacy	1	2	2
Match in logic, language, experience	1	1	2
Cultural image and examples	N/A	N/A	N/A
TOTAL	19	25	25
NUMBER N/A	5	5	5
#N/A x2	10	10	10
44 - N/Ax2 (Revised maximum score)	34	34	34
TOTAL / Revised Max	0.55882353	0.73529412	0.73529412
Interpretation	Adequate	Superior	Superior

Table 21. SAM ratings part 8

	Genetic testing: what you should know	Genetic testing: what you should know	Genetic testing: what you should know
Reviewer	A	B	C
Purpose is Evident	1	2	1
Content about behaviors	1	2	1
Scope is limited	2	2	2
Summary or review included	0	0	0
Reading grade level	2	2	2
Writing style, active voice	1	2	2
Vocabulary uses common words	1	2	1
Context is given first	2	2	2
Learning aids via road signs, subtitles, captions	1	2	1
Cover graphic shows purpose	1	1	1
Types of graphics	1	1	1
Relevance of illustrations	1	1	1
Lists and tables explained	N/A	N/A	N/A
Captions used for graphics	N/A	N/A	N/A
Layout factors	1	1	2
Typography	2	2	2
Subheads "chunking" used	2	1	2
Interaction used	0	0	1
Behaviors are modeled and specific	1	1	1
Motivation, self-efficacy	1	2	1
Match in logic, language, experience	1	1	1
Cultural image and examples	1	1	1
TOTAL	23	28	24
NUMBER N/A	2	2	2
#N/A x2	4	4	4
44 - N/Ax2 (Revised maximum score)	40	40	40
TOTAL / Revised Max	0.575	0.7	0.6
Interpretation	Adequate	Superior	Adequate

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