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ARTICLE

Informal prenatal genetic screening education: What can you learn from Google and YouTube?

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ABSTRACT

Purpose: The goal of this article is to explore what online education and decision support tools are freely available to patients about prenatal screening.

Methods: We (1) conducted an environmental scan using Google Trends to identify and evaluate prenatal screening search terms, (2) created a list of websites and YouTube videos that would be easily accessed by a searcher, and (3) characterized the information within those websites and videos, including an examination of their qualities as a decision support tool and a readability analysis.

Results: Fifty websites, containing 62 unique educational resources, and 39 YouTube videos were analyzed. The websites were primarily educational, although the education was provided by a range of sources, including non-profit and for-profit organizations, universities, and governments (ie, public health departments). Readability scores of Patient Education Materials Assessment Tool for Printable Materials for the sites ranged from 50% to 92%, with a median score of 74%. Two of the websites we evaluated met all of the limited decision support standards we applied; 4 of the websites included patient stories or experiences, and 8 included some element of values clarification. Videos were more likely to include values clarification.

Conclusion: The information available to patients online is variable. Although most is balanced and informative, much is difficult to read and missing key decision-making factors. Health care providers should work with patients to ensure they have basic comprehension of the prenatal genetic screening materials, possible result outcomes, and expected steps following a positive screening result.

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Introduction

Advancements in genetic testing have changed the landscape for pregnant people looking to learn about the chance that their fetus may have a chromosomal or genetic condition. Although these opportunities have historically been offered to families with a history of genetic or chromosomal conditions, the American College of Obstetrics and Gynecologists recommends that all pregnant individuals be offered prenatal genetic testing as part of their prenatal care[1] regardless of maternal age, disease, history, or risk status.

With the increased use of these genetic tests during pregnancy (ie, genetic testing is more accessible and less expensive), it is critical that people are informed and understand the purpose of the tests and their potential implications. Additionally, decision making based on risks to one's health can increase anxiety, regret, or unnecessary health care utilization.[2] These mental health risks are amplified during pregnancy and have a direct impact on the health and longevity of the fetus.[3]

Traditional invasive prenatal diagnostic tests, such as amniocentesis and chorionic villus sampling, yield the most accurate diagnosis but carry a risk of miscarriage.[4] Providers typically offer a less invasive first line screening test. Although prenatal cell-free DNA screening (cfDNA) is the most accurate among screening tests, it still has a small false-positive rate. As a result, patients may require confirmatory testing, either prenatally or after birth.[5] However, if a person does not understand the potential results and implications from the screening test, they may experience unnecessary stress or potentially choose to terminate before diagnostic confirmation.[6,7] Therefore, it is important for pregnant couples to make informed decisions about genetic testing. The risks and ethics involved in the decision emphasize the need for educating pregnant people in advance of actual testing.[8,9]

Ineffective education could prove harmful to patients, especially when faced with unfamiliar concepts (eg, false-positive results and probability) and the implications of follow-up diagnostic testing.[10] However, an increasing number of physicians and patients view cfDNA as routine, because of the flexibility for use both early and late in the pregnancy and the ease of testing with a blood test.[11,12] Even commercial companies offer cfDNA outside of the clinic to "find out your baby's gender," eg, Peek-a-boo Early Detection Gender DNA Test (for the purposes of this article, we use the word "gender" because it is the word used by the Peek-a-boo company; in actuality, these tests provide information about the biological sex of the fetus). There is concern that routinization may lead to reduced education and potentially increased anxiety for the pregnant person between the time they receive "high-risk" results for an aneuploidy and the follow-up explanation with their physician.[13] Genetic counseling may alleviate anxiety when done before screening, but there are a limited number of genetic counselors available. Thus, there is a significant need for accessible mechanisms to better inform pregnant couples about prenatal screening options and the growing complexities of emerging medical advancements during pregnancy.

Any educational mechanism should recognize that the choice to complete prenatal genetic screening is a personal decision that should be guided by individual values. Prenatal screening may be presented to patients as simple and routine,[8] ignoring the values inherent to the decision, particularly if termination is an option. A systematic review of qualitative research involving adult women who had undergone cfDNA revealed that many of them were dissatisfied with their experience because they felt that their clinician was not informed enough to help them decide.[11]

Use of educational decision support tools

One approach for informing pregnant couples about their options around prenatal screening is the use of decision support tools (DSTs). Leiva Portocarrero et al[14] found that most pregnant people want to be involved in decision making regarding prenatal testing; yet, they are mostly influenced by the information they get from their providers[2] and societal or cultural influences.[12] Given wide differences in provider knowledge, time available for discussion, or interest in the conversation, a DST can help patients make informed decisions based on their personal values and expectations.[2]

A good DST will provide accurate information about available options while also presenting potential outcomes and the benefits and risks associated with a given decision.[3] Additionally, it will help a patient to clarify their values associated with the decision, support patients' preferences, and enable patients to actively engage in shared decision making with their providers. DSTs have been shown to (1) increase knowledge of the diagnosis and treatment options, (2) improve accuracy of risk perception, (3) improve congruency between values and care choices, (4) decrease decisional conflict, (5) increase patient participation in shared decision making, and (6) improve patient-provider communication.[15] The goal of DST use in and around pregnancy is not to eliminate physicians' consultation but to provide patients with information that helps them share in the decision-making process.[2]

The gold standard DST meets the International Patient Decision Support (IPDAS) collaboration standards, which consists of 16 requirements.[16] IPDAS requires DSTs to support people's decision-making regarding health care options, provide information about options, and help patients articulate and communicate their personal values. Few tools meet all 16 IPDAS requirements[14]; yet, several studies have shown a positive impact of DSTs that do not meet the full requirements. For instance, prenatal screening decision making is improved by DSTs by improving knowledge scores and decreasing decision-making conflicts.[2] Additionally, informal information sources, such as those found through a Google search, also influence decision-making processes in pregnancy.[17] Given the potential impact of any information source, but particularly one that meets certain standards, this study evaluated how well educational resources available online met select IPDAS qualifications. Meeting the full IPDAS industry standards was not the goal of our evaluation in this study. Instead, we looked at some broad categories that are generally accepted as important components of a decision support tool.

Objective

The goal of this article is to explore what online education and DSTs are freely available to patients about prenatal screening. Researchers have created and assessed numerous DSTs,[18-24] but these aids are typically not available for use once the research project has ended. Given the importance of these informal information sources, our research team aimed to present an overview of the available information found using the search engines Google and YouTube to identify gaps in knowledge and resources, with the long-term goal of stimulating more research in this area.

Methods

To meet our objective, we (1) conducted an environmental scan using Google Trends to identify and evaluate prenatal screening search terms, (2) created a list of websites and YouTube videos that would be easily accessed by a searcher, and (3) characterized the information within those websites and videos using a qualitative descriptive framework.[25]

Environmental scan

An environmental scan was conducted to find relevant websites that may provide patient-facing information about prenatal screening. To begin the scan, websites known to the research team as strong sources of information were listed and reviewed. Google Trends was then used to systematically identify alternative search queries (Related Queries) or synonyms, which were subsequently entered into the Google search engine to identify other possible websites patients may find in their own search. Finally, we widened the environmental scan to include YouTube, using the same search terms to explore relevant videos.

Google Trends

Google Trends (https://trends.google.com/trends/?geo=US) is a website that allows users to identify the popularity of search queries done in the Google search engine. Google Trends results include Interest by Subregion, Measure of Interest, Related Topics, Related Queries, and Measures of relatedness for the related topics and related queries.

For this analysis, the term prenatal screening was entered into Google Trends on October 17, 2022, using Google Trends parameters: limited to the United States, the past 12 months, all categories, and Web searches. Synonyms of related queries were then searched, and related query synonyms of those terms were searched and so on, until no new synonyms were found. Specific prenatal screening brand names were excluded from this analysis.

Website and YouTube analysis

The research team analyzed the websites pulled from the Google Trends process. One team member summarized each prenatal genetic screening website, and a second team member independently reviewed their assessments. Any discrepancies were evaluated and agreed upon together.

The team visited and analyzed select sites known to contain relevant educational sources and the top 9 websites from each Google term search, using incognito mode so as not to influence the search by past search history, excluding advertisements labeled as such at the top of the search page. For each website the following information was gathered: Organization, Description of Site, URL, Organization Location, Profit Status (nonprofit vs for profit), Affiliated Organizations, Sponsor/Funder, and Educational Resource Offered. A single site may offer multiple educational resources, such as infographic downloads and videos. For each Educational Resource we assessed the following: Resource Title, Type (written text, video, graphic: infographic, graphic: comic, graphic: other, print materials, live workshops or presentations, and other), Brief Description, Specific URL, and whether or not select elements of the IPDAS had been met. The 16 standards developed by IPDAS were not appropriate to apply to the websites because the websites were not intended to be DSTs. Instead, we chose key “qualifying criteria” elements that any patient DST should meet.[16] These included the following: the resource presented relevant information (ie, anything factual about the screening); the resource presented personal experiences (eg, 1 woman telling her story about the aftermath of her decision), the resource helped patients clarify values by providing questions (eg, “How important is it to you to know that your pregnancy has a condition such as Down syndrome?”), the resource helped the user plan for next steps (eg, an explanation of what happens after receiving the prenatal screening results); the resource was neutral and balanced about the decision to be made (defined as organized, as much as possible, in a manner that is objective, nondirective, and does not favor one option over another).

The research team next explored YouTube as a separate and independent source of relevant information. Team members systematically documented videos on YouTube associated with the same Google search terms, gathering the same pieces of information about the videos when possible.

After the initial analysis was completed, the research team assessed the readability of the websites found when entering the Google Trends terms into the Google search engine, utilizing the Patient Education Materials Assessment

Tool for Printable Materials (PEMAT-P) "understandability" score.[18] The "understandability" score is based on 19 questions about the material's content, word choice and style, use of numbers, organization, layout and design, and use of visual aids. The high score available for a given site is variable because some categories may not be applicable. For example, if the website did not offer any visual aids, this would be marked as a "No" in the first visual aid question and then follow-up questions would be marked as "Not Applicable," reducing the total possible score for that site. The PEMAT-P score, which is a percentage of the total PEMAT-P criteria the educational material contains, provides a metric to compare sites with each other and does not include threshold values to rate quality. Two research team members applied the PEMAT-P to the first 5 websites of each search term discovered through the Google Trends results, because more than two-thirds of users limit their interaction to the first 5 results, with the remaining 5 results receiving just 3.73% of the clicks.[26,27] Utilizing double coding, each site was independently rated by 2 different coders. The resulting percentage scores (number of questions endorsed divided by the total possible points) for each site were compared across raters and differences of 10% or more were discussed and resolved.

Results

Google Trends analysis

The term prenatal screening returned 59 unique Related Queries in Google Trends. Table 1 summarizes the major categories of the unique queries resulting from Google Trends into prenatal genetic screening related terms, terms phrased as a question, and terms including the word "gender" because this was a common category. We excluded query results for different types of screening tests (eg, carrier screening), diagnostic tests (eg, amniocentesis), names of specific genetic conditions (eg, cystic fibrosis), questions related to cost or location, or prenatal screening name brands (eg, Panorama). For a full list of Related Queries results, see Supplemental Table 1.

Website and YouTube video analysis

Fifty unique sites resulted from the prenatal screening Google Trends terms entered into the Google search engine and the websites identified a priori by the research team as known educational resources. Of those 50, 4 were sales sites (eg, Amazon) selling a noninvasive "gender reveal" prenatal test that could be purchased and completed from home, only 1 of which provided some educational information. The follow-up exploration of YouTube videos revealed 39 unique YouTube videos discussing prenatal screening. See Table 2 for a breakdown of sites based on type, profit status, and funding organization and how those groups rated on the

Table 1 Google Trends related queries to "Prenatal Screening" by search term category

Prenatal Screening	Related Queries From Google Trends
	Cell free DNA test
	First trimester genetic screening
	First trimester screening
	genetic blood testing pregnancy
	Genetic screening pregnancy
	Genetic testing during pregnancy
	Genetic testing during pregnancy first trimester
	Genetic testing for pregnancy
	genetic testing in pregnancy
	Genetic testing pregnancy
	Maternal serum screening
	NIPT
	NIPT blood test
	NIPT genetic testing
	NIPT pregnancy
	NIPT screening
	NIPT test
	NIPT test pregnancy
	NIPT testing
	Noninvasive prenatal testing
	Noninvasive prenatal screening
	Prenatal DNA testing
	Prenatal genetic screening
	prenatal genetic testing
	prenatal screening
	Prenatal screening test
	Prenatal screening tests
	Prenatal testing
Phrased as a question	
	What does NIPT test for
	What does the NIPT test for
	What is a NIPT test
	What is an NIPT test
	What is genetic testing during pregnancy
	What is genetic testing pregnancy
	What is NIPT
	What is NIPT test
	What is NIPT test in pregnancy
	What is NIPT testing in pregnancy
	What is prenatal testing
Search terms with "gender"	
	Baby gender blood test
	Blood test for baby gender
	Blood test for gender
	Blood test for gender of baby
	Blood test for gender reveal
	Blood test to determine gender
	Blood test to determine gender of baby
	Blood test to find out gender
	Does NIPT test for gender
	Early gender blood test
	Early gender test
	Gender blood test
	Gender blood test at doctor's office

(continued)

Table 1 Continued

Prenatal Screening	Related Queries From Google Trends
	Gender reveal blood test
	Genetic blood testing pregnancy gender
	Genetic testing pregnancy gender
	NIPT blood test gender
	NIPT gender test
	NIPT test gender
	Pregnancy gender blood test

different IPDAS criteria. The for-profit organizations were typically labs, private health clinics, or direct sales sites for the "gender reveal" test that included more education than that offered by places such as Amazon.

Of the 50 sites, 62 unique educational resources were identified; some of the websites had multiple resources available, such as both written text and an embedded video. Among the 62 resources, 49 offered written text, 3 offered video, 2 offered infographics, and 5 offered print materials for download (eg, brochure). Three were only selling a cfDNA-based test for biological sex and offered no educational value. None offered additional educational graphics.

Each educational resource was analyzed for IPDAS elements. Only 4 resources met all 5 IPDAS qualifying criteria we chose for this study. The majority of the resources presented relevant information ($n = 54$, 87%) and were neutral and balanced about the decision to be made ($n = 55$, 88.7%), but only 6.5% ($n = 4$) presented individual experiences and 11.3% ($n = 7$) included some level of values clarification exercises. The type of site did not appear to affect results on the IPDAS criteria (Table 2), but statistical analyses were not completed because of low numbers. Of the groups with at least 10 resources (nonprofit, for profit, and government), non-profit sites were more likely to present values clarification questions (20% vs 6% and 10%) and government sites were least likely to help the user prepare for next steps (50% vs 76% and 80%).

Analysis of the YouTube videos was approached in the same manner as the websites. Of the 39 videos, the majority (56%) were made by non-profit organizations and 20% were made by for-profit organizations (laboratories) (Table 2). The IPDAS criteria met by the videos can be seen in Table 2. Similar to the websites, all the videos present information in a neutral and balanced manner, and only 2 present unique patient experiences. However, the percentage of videos encouraging some level of values clarification ($n = 18$, 46%) was higher than the percentage of websites encouraging values clarification ($n = 7$, 11.3%).

A high number of websites only offered written text; therefore, the research team conducted a readability analysis using the Understandability component of the PEMAT-P. After deduplicating the 5 top results of the Google search using each of the Google Trends terms, 30 websites remained and were scored by 2 independent raters. The resulting PEMAT-P Understandability score of the websites analyzed ranged from 50% to 92%, with a median score of 74%. PEMAT-P average score for the different site types explored above (Table 3) revealed much lower scores for the "Other" (53.9%) and the "Direct Sales" (66.3%) categories, compared with nonprofit (76.8%) and for profit (72.3%). However, the number of sites assessed for both of these groups was small. Twenty five or more of the 30 sites met 7 of the PEMAT-P Understandability criteria (Table 4). Three of the PEMAT-P Understandability criteria were met less than half of the time. Additionally, only 3 of the 30 websites contained visual aids to make the content more easily understood. Two sites included tables, both of which were clinician-focused. Finally, many of the websites, from both commercial and non-profit sources, contained distracting

Table 2 Select IPDAS criteria applied to websites and YouTube videos

Site Type	Present Relevant Information?	Present Experiences?	Values Clarification?	Help User Plan for Next Steps?	Neutral And Balanced About the Decision to Be Made?
	Websites				
Non-profit sites ($n = 25$)[a]	24 (96%)	2 (8%)	5 (20%)	20 (80%)	24 (96%)
For profit sites ($n = 17$)	14 (82%)	0 (0%)	1 (6%)	13 (76%)	15 (88%)
Government ($n = 10$)	9 (90%)	1 (10%)	1 (10%)	5 (50%)	10 (100%)
University ($n = 3$)	3 (100%)	0 (0%)	1 (33%)	3 (100%)	3 (100%)
Other ($n = 3$)[b]	3 (100%)	1 (33%)	0 (0%)	1 (33%)	3 (100%)
Direct Sales ($n = 4$)	1 (25%)	0 (0%)	0 (0%)	1 (25%)	0 (0%)
	YouTube Videos				
Non-profit sites ($n = 22$)	22 (100%)	0 (0%)	10 (46%)	17 (77%)	21 (96%)
For profit sites ($n = 8$)	8 (100%)	1 (13%)	4 (50%)	8 (100%)	8 (100%)
Government ($n = 4$)	4 (100%)	1 (25%)	2 (50%)	4 (100%)	3 (75%)
University ($n = 4$)	4 (100%)	0 (0%)	1 (25%)	3 (75%)	4 (100%)
Unknown ($n = 1$)[c]	1 (100%)	0 (0%)	1 (100%)	1 (100%)	1 (100%)

[a] Provided n's for websites refers to the total number of resources available. Actual number of sites accessed includes 18 non-profits, 13 for-profits, 9 government, 3 university, 3 other, and 4 direct sales.

[b] Other: Peer-reviewed journal articles and newspaper articles.

[c] The authors were unable to determine to which category the unknown video producer belonged.

Table 3 PEMAT average scores for sites reviewed in PEMAT sub-analysis

PEMAT	Non-profit Sites (n = 7)	For Profit Sites (n = 11)	Government (n = 7)	Other (n = 2)[a]	Direct Sales (n = 3)
Average PEMAT Score	76.79	72.27	75.84	53.85	66.3

[a] Other: peer-reviewed journal articles.

advertisements and videos unrelated to the subject, affecting readability in a way that may not be well captured by the PEMAT-P.

Discussion

Screening for congenital anomalies is recommended for all pregnant people regardless of age and family history.[14] Given the high amount of information covered in prenatal clinical visits and the limited time available during the visits, the need to educate people on prenatal screening outside of the clinic has been clear for many years. Various educational approaches for prenatal genetic screening, both electronic and paper-based, have been created and assessed by researchers in the past decade.[18-24,28-30] These studies clearly indicate that users gain knowledge about prenatal genetic screening after using the educational tool. However, these

Table 4 PEMAT-P understandability scoring

PEMAT-P Category	PEMAT-P Criteria	# of Sites Out of 30 (Mean of 2 Reviewer Scores)
Content	1. The material makes its purpose completely evident. [Disagree = 0, Agree = 1]	28
	2. The material does not include information or content that distracts from its purpose. [Disagree = 0, Agree = 1]	25.5
Word Choice and Style	3. The material uses common, everyday language. [Disagree = 0, Agree = 1]	20.5
	4. Medical terms are used only to familiarize audience with the terms. When used, medical terms are defined, but not through use of another link. [Disagree = 0, Agree = 1]	22
	5. The material uses the active voice. [Disagree = 0, Agree = 1]	25.5
Use of Numbers	6. Numbers appearing in the material are clear and easy to understand (ie, whole numbers, not fractions or percentages). [Disagree = 0, Agree = 1]	12.5
	7. The material does not expect the user to perform calculations. [Disagree = 0, Agree = 1]	30
Organization	8. The material breaks or “chunks” information into short sections. [Disagree = 0, Agree = 1, Very short material = N/A]	28
	9. The material’s sections have informative headers. [Disagree = 0, Agree = 1, Very short material = N/A]	24.5
	10. The material presents information in a logical sequence. [Disagree = 0, Agree = 1]	28.5
	11. The material provides a summary. [Disagree = 0, Agree = 1, Very short material = N/A]	9.5
Layout & Design	12. The material uses visual cues (eg, arrows, boxes, bullets, bold, larger font, and highlighting) to draw attention to key points. [Disagree = 0, Agree = 1, Video = N/A]	23.5
Use of Visual Aids	15. The material uses visual aids whenever they could make content more easily understood (eg, illustration of healthy portion size). [Disagree = 0, Agree = 1]	3
	16. The material’s visual aids reinforce rather than distract from the content. [Disagree = 0, Agree = 1, No visual aids = N/A]	3.5
	17. The material’s visual aids have clear titles or captions. [Disagree = 0, Agree = 1, No visual aids = N/A]	3.5
	18. The material uses illustrations and photographs that are clear and uncluttered. [Disagree = 0, Agree = 1, No visual aids = N/A]	5
	19. The material uses simple tables with short and clear row and column headings. [Disagree = 0, Agree = 1, No tables = N/A]	0.5

educational tools are not available to patients who are actively looking for information on prenatal genetic screening on their own, and current attempts to track down the original DSTs[18-24] indicate that the tools are also no longer in use clinically. It is likely that most patients are not aware of these tools; therefore, they turn to informal sources of information, such as friends or the internet.[11] Thus, the goal of this project was to explore what informal educational resources are available to patients who turn to the internet for understanding.

This environmental scan analyzed 50 websites containing a total of 62 unique educational sources. The websites appearing from these Google searches were primarily educational sites (as opposed to blogs and commercial advertising), although the education was being provided by a range of sources including non-profit organizations, for-profit organizations, Universities, and governments (ie, public health departments) (Table 2). People are typically taught that .gov and.edu are more trustworthy sources of information, but these sources were in the minority of what appeared through the Google searches, with only 13 sites having these top-level domains. In contrast, non-profit (.org) sites can be advocacy groups that have a particular bias.[31] However, we found 96% of the resources provided by these sites included balanced information. As expected, for-profit websites encouraged use of their product or clinic; yet, we found that they still provided balanced information about the screening itself (88%).

Most of the informal information sources available to the general public are primarily text-based unless the user directly searches within YouTube. The abundance of text-based resources may be problematic for people with low health literacy. Our readability analysis revealed that the readability of text sources supplied by the Google search was broad, ranging from 50% to 92% scores on the PEMAT-P. Results from the PEMAT-P also show that a majority of websites make their purpose clear, do not expect the user to perform calculations, and enhance readability by breaking up the material into short sections with informative headers, and roughly two-thirds of the sites used language that could be considered common, everyday language. Yet, very few sites provide a summary or include visual aids, such as an image visually representing the probability of a high-risk result, alongside the text to help readers understand the material. Additionally, nearly 10% also included a high number of distracting advertisements.

It is important to note that a Google search provides information for a wide target audience, including people seeking education or professional guidance or looking to purchase a product. This broad response may make it difficult for patients to wade through and determine what is appropriate information. Although most of the sites we evaluated appeared to be intended as patient-facing (compared with clinician-facing), and those sites had reasonable readability scores, they did not meet the limited IPDAS standards we applied for this study. Only 4 of the resources included patient stories or experiences, and only 8 included some element of values clarification. Notably, 3 of those 8 resources only included implicit values clarification, simply encouraging people to think about what matters to them. A recent meta-analysis concluded that explicit values clarification methods are helpful for making values-congruent decisions but that decisional conflict does not differ between explicit and implicit methods of presentation.[32]

The sites that did include personal stories were varied in their approach. For instance, 1 site put together a downloadable PDF that walks a parent through the facts and emotions around receiving a Down syndrome diagnosis. Another posted a video on their website that presents the screening decision through the eyes of 1 patient, “Louisa.” In comparison, stories presented by a national newspaper or a blog post present personal stories without as much factual information or values clarification opportunities. It is important to note that recent research indicates that the primary factor impacting behavior change is the degree to which the personal narrative resonates with the viewer, not merely the inclusion of the story itself.[33] Thus, it appears that individuals searching for education about prenatal screening can find relevant, unbiased, information but may not have what they need to make a values-appropriate decision.

Results from our video-specific exploration were similar. Video-based presentations can display complex information in a culturally and linguistically appropriate format to individuals of diverse educational backgrounds, making them ideal for presenting health-care-related information (Johnson, 2023, Unpublished data).[31,32] Videos are also helpful for individuals with low literacy. According to a 2004 Institute of Medicine report, at least 90 million adults do not have the literacy skills required to effectively navigate the US health system.[34] Genetic screening is a complex topic, often accompanied by jargon unfamiliar to those outside of the field, which can make comprehension even more challenging for those with low literacy skills. Of the 39 YouTube videos assessed here, only 2 included personal stories. This is a missed opportunity for a medium that easily can incorporate personal stories. However, the videos were more likely than the websites to discuss how personal values might be considered in decision making.

Clinical considerations

People seeking additional information about prenatal screening outside of their clinical visit are already taking an extra step. If prenatal genetic screening is presented to patients as routine with little discussion in advance, patients may not also be presented with additional information about the potential risks. However, if patients turn to the internet, much of the information that exists through a Google search also presents prenatal genetic screening as a “simple blood test” or as a method to learn about the sex of the baby early. Thus, despite the factual information being presented, patients may walk away from their search unprepared for a positive (or “high-risk”) screening result.

Several prenatal screening laboratories showed up in our Google search. The direct-to-consumer advertising done by labs or other commercial websites may minimize or neglect all mention of the potential risks while highlighting the ease and accuracy of the tests.[6,35-38] For example, the three clinic websites we examined presented cfDNA primarily as an early "gender identification test" and only 1 of them presented information in a neutral manner. The cfDNA tests (often referred to as noninvasive prenatal tests within the websites) are not FDA evaluated and approved because they are laboratory developed tests. Without direct regulation of genetic testing and the lack of a centralized health care system, the implementation of cfDNA tests in the US has been influenced by the commercial sector, medical professional associations, and private insurers.[39,40] The result is variable insurance coverage and variable options offered to patients, depending on their clinic.[41] Consequently, patients may be offered lab tests for microdeletions alongside aneuploidies and not recognize the difference due to inadequate or limited education, despite the fact testing for microdeletions is not recommended by the FDA[42] or ACOG.[43]

Additionally, because cfDNA-based screens can be used so early in pregnancy and detect conditions for which there is no cure, it may be used primarily by some people to determine the need for termination.[37] Without adequate education, patients may terminate based on a screening result before conducting confirmatory testing because of limited understanding of the concept of risk or probability. Conversely, patients may have increased anxiety related to the test if they receive a high-risk result but live in a state that does not allow termination or choose not to do invasive testing, leaving them unclear about what to do.[44,45]

One final consideration is the impact of informal information on a pregnant person's mental health. Sanders and Crozier[17] found that as a result of exploring informal information sources, women experienced both anxiety and feelings of empowerment. The perception of control and empowerment, created by forming a strong knowledge base, breaks down as soon as something goes wrong or a result is unexpected, resulting in increased anxiety. Additionally, the authors discussed an "Information Heaven and Hell" dichotomy because of the findings that people are happy to have access to more information, but too much information can result in feeling overwhelmed.[17] Although curating information for a patient could be helpful to sort out this dichotomy, patients may still dig into informal information sources away from the provided resource.

Strengths and limitations

To our knowledge, this is a unique approach to assess publicly available information for prenatal genetic screening based on a simple search from popular internet sources. However, a limitation of this study is the lack of knowledge about how people are actually searching for information. Given the market saturation of Google, we only explored search results within this 1 search engine but have not addressed additional search engines such as DuckDuckGo, Yahoo, etc. Additionally, we started our Google Trends analysis with an academic term, prenatal screening. The Trends analysis provided dozens of additional search terms, but the resulting pages may not have captured results starting with more informal search terms. Another limitation is that this study did not include social media and online forums where people may be gathering information.

Finally, our analysis of text readability was useful for recognizing literacy concerns, but we did not have a standardized tool to assess content. Often a site would yield a higher readability score but would have questionable content, from the point of view of the authors.

Takeaways

- The information available to patients online is variable. Although most is balanced and informative, many websites could improve readability and add key decision-making factors
- Providers should work with patients to ensure they have basic comprehension of the prenatal genetic screening material and next steps
- This exploration provided an initial snapshot of what is available for patients seeking information about prenatal screening on their own. Future work could explore social media, carrier screening, and a more in-depth readability analysis

Data Availability

The data that support the findings of this study are available on request from the corresponding author. The data are not currently publicly available.

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Ethics Declaration

This study did not include human subjects and therefore was not reviewed by an institutional review board.

Conflict of Interest

The authors declare no conflicts of interest.

Additional Information

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