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ORIGINAL ARTICLE

Genetic testing and eHealth usage among Deaf women

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Abstract

In the past decade, accessible information in American Sign Language (ASL) about cancer and genetic testing is expanding on eHealth platforms, including social network sites, commercial sites, and mobile apps. Primary data on genetic testing awareness and genetic testing for *BRCA 1/2* among Deaf women were gathered using HINTS-ASL survey between November 2016 and April 2018, and secondary data for hearing women were drawn from NCI's HINTS 5 Cycle 1 survey in 2017. Deaf women who had heard of DNA testing (63%) were more likely to be young adults, college graduates, and/or have a family history of cancer. Compared to hearing women, Deaf women who had heard of genetic testing were more likely to use social networking sites to read or share information about medical topics and watch health-related videos. Making eHealth platforms accessible in ASL and easy-to-understand text can help reduce knowledge gap in genetic testing, since some Deaf women may not be using genetic testing to help identify whether they are at increased risk for breast and ovarian cancer early on, before they are diagnosed with cancer.

KEYWORDS
deaf, disability, disparities, DNA, eHealth, genetic counseling, genetic knowledge, genetic testing, hereditary breast cancer, sign language, women

1 | INTRODUCTION

Women have a one in eight chance of developing breast cancer in their lifetime (Noone et al., 2018). Therefore, the discovery of the link between *BRCA1* and *BRCA2* (*BRCA 1/2*) genes and breast cancer has been among the most well-known and publicly discussed genetic links. Knowing that a woman has inherited a pathogenic variant in a *BRCA* 1/2 gene can alert her to her increased risk of developing breast cancer. Thus, the availability of genetic testing to identify the presence of pathogenic variants in *BRCA 1/2* genes has become an extremely beneficial tool to help women and their clinicians assess their personal breast cancer risk and evaluate their clinical options.

Deaf women experience multiple barriers to accessing complex health information, placing them at increased risk of being poorly informed and even misinformed on this important and rapidly evolving health topic. Primary or monolingual users of American Sign Language (ASL) can have a lower average level of English language literacy in comparison to native English speakers, which is common among those who learn English as a second language (Koulidobrova, Kuntze, & Dostal, 2018). Consequently, some Deaf women may find the Internet difficult to navigate and comprehend (Kushalnagar et al., 2015). The lack of or reduced access to health-related information contributes to creating disparities in *BRCA 1/2* breast cancer knowledge among Deaf women who use ASL. In spite of this known access barrier, a national study conducted during 2016 and 2017 found that the majority of Deaf participants went to the Internet as their first source of health information (Kushalnagar & Kushalnagar, 2018).

Further complicating this issue for Deaf women is that both reliable and unreliable genetic-related information has become increasingly available and rapidly disseminated on various electronic platforms, such as eHealth, YouTube, and social media sites (Karras & Rintamaki, 2012; Suggs, 2006). Equally important, impersonal online discussions of genetically linked diseases can be quite different from the very personal discussion that takes place between patients and their providers after receiving a positive test result. Knowing that one has inherited a pathogenic variant in a *BRCA 1/2* gene and

has an increased risk of developing a variety of cancers can be a highly distressing experience for women and their loved ones (Fisher et al., 2017), some of whom may share the familial genetic makeup. Suddenly the previously generic discussions can take on a very personal focus, often with confusing results (Fisher et al., 2017).

The field of genetic counseling has evolved to help patients gain a better understanding of their genetic profile and their risk of developing breast cancer and other diseases during their lifetime. In particular, a genetic counselor can help explain the personal implications of having a pathogenic variant in a *BRCA 1/2* gene and subsequent intervention options, making genetic counselors a valuable resource to help patients assess their personal breast cancer risk and options. To take advantage of genetic counselors, Deaf women must first know the basic information about genetic testing to spur their interest in exploring its personal relevance. Deaf women then must know where to find more detailed, accessible health information required to decide whether genetic testing is likely to be of personal value.

1.1 | Deaf individuals and breast cancer knowledge

Currently, there are existing disparities in breast cancer knowledge among Deaf women who use ASL. Between 2002 and 2003, seven Deaf female breast cancer survivors from the Los Angeles area were interviewed about their breast cancer knowledge (Berman et al., 2017). Qualitative data from those participants suggested that even after going through the process of a breast cancer diagnosis, its treatment, and subsequent recovery, these Deaf breast cancer survivors still had inadequate breast cancer knowledge. This study was conducted before the widespread use of the Internet; thus, it is critical to also include studies that were influenced by the Internet in order to analyze the impact of eHealth platforms on breast cancer knowledge.

A breast cancer knowledge and screening practices survey from 2008 to 2009 that was administered in English and ASL to 209 Deaf women who were at least 40 years old also indicated lack of knowledge about breast cancer (Berman et al., 2013). Of the 197 women who responded to the question, "Which of the following increases your risk of getting breast cancer?" 33% incorrectly answered that "hitting or bumping breasts" increases one's risk, while only 14.7% and 26.9% correctly agreed with statements that being obese and having late menopause after age 55 increases one's risk of breast cancer, respectively. The authors also reported significantly higher knowledge of mammography purpose among women who had seen a doctor within the previous year compared to women who had not.

However, accessible health information can help increase Deaf women's breast cancer knowledge. An ASL video-based education program about breast cancer using 2002–2009 guidelines from the American Cancer Society and National Cancer Institute (NCI) and administered in the form of a health education program for the Deaf community in southern California showed promising results (Hickey et al., 2013). A test–retest survey with 122 Deaf, ASL-using women showed significant improvement in breast cancer knowledge after watching the video in ASL.

1.2 | Direct-to-consumer genetic tests and eHealth platforms for disseminating genetic information

In 2013, the U.S. Supreme Court ruled that "a naturally occurring DNA segment is a product of nature and not patent eligible merely because it has been isolated" (Association for Molecular Pathology v. Myriad Genetics, July 13, 2013). That landmark decision opened the floodgates for competitive marketing on genetic testing for diseases (Hooker et al., 2017). When genetic testing was first available, it could only be performed with a doctor's order. In recent years, direct-to-consumer (DTC) genetic tests have become readily available to the public. The marketing efforts that have accompanied these changes have been another means of expanding the public's knowledge about the potential benefits of genetic testing.

Using data from the 2013 U.S. Health Information National Trends (HINTS) survey, Agurs-Collins et al. (2015) investigated the general population's awareness of DTC genetic testing. Only 35.6% of the 3,185 participants surveyed were aware of DTC genetic tests, having heard of DTC genetic tests through the radio, television, and Internet. However, for the Deaf community, information disseminated through the radio and television can be inaccessible. The information presented can be at an inaccessible literacy level, along with lack of ASL and accurate, live captions. Similarly, information disseminated via the Internet can be at an inaccessible English literacy level and videos conveying information about breast cancer and *BRCA 1/2* pathogenic variants are rarely available in ASL.

1.3 | Deaf individuals and genetics knowledge

Between November 2013 and May 2014, the Deaf Genetics Project team created an online "Cancer Genetics Education Module" to increase Deaf individuals' cancer awareness of genetic testing through a fully accessible language platform in ASL and English (Boudreault et al., 2018). In the creation of this online module, a focus group of 19 Deaf or hard-of-hearing participants was created to gather suggestions about the online platform. Within this focus group, 12 Deaf participants' baseline genetic and genetic counseling-related knowledge were gathered in addition to their family history of cancer. Participants were asked, "*Have you seen the word _____ in written materials?*" Nearly all of the participants (92%) recognized the term "genetic counseling," while 75% of participants had seen both the terms "gene" and "genetic testing" in print. However, when genetic terms became more specific, there was less word recognition among the sample. When participants were asked if they had seen the term "mutation" in print, only 33% reported "yes." When asked about the term "*BRCA1*," none of the participants recognized the term.

In the years since those various studies have been conducted, ASL-accessible information about breast cancer and genetic testing has continued to expand on the Internet. These include ASL health videos produced by the University of California San Diego's ASL Cancer Program, an ASL health film about genetic testing for breast cancer produced by the National Human Genome Research Institute in collaboration with the Deaf Health Communication and Quality of

Life Center at Gallaudet University, and ASL-interpreted "USH Talks" by Usher Syndrome Coalition.

1.4 | eHealth and accessibility

It is important to ensure that eHealth platforms are accessible for Deaf consumers. Two recent studies concluded that eHealth platforms should use English vocabulary and syntax that is written below a sixth-grade reading level, as well as ASL, while still retaining the complete content of the originally conveyed cancer health information (Boudreault et al., 2018; Kushalnagar et al., 2016). These modifications have been shown to make a significant improvement in a Deaf individual's understanding of health information.

In a sample of 36 Deaf and 38 hearing college students, health and cancer texts were presented in their original form as found online along with a simplified version that consisted of English at a fourth-grade level (Kushalnagar et al., 2016). Compared to their comprehension of the original text, Deaf college students displayed significantly higher levels of comprehension with the simplified English text. Thus, the use of ASL along with the inclusion of simplified text on eHealth platforms are two important factors that can help increase Deaf individuals' health knowledge through the Internet.

This study investigates Deaf women's current awareness of genetic testing, as well as their use of *BRCA ½* genetic testing, to gain a better understanding of which subgroup(s) are at a greater risk for low awareness of genetic testing and underutilization of *BRCA ½* genetic testing. This study also evaluates Deaf women's use of eHealth platforms for health-related issues and whether there is a relationship between Deaf women's awareness of genetic testing and use of eHealth platforms.

2 | METHODS

2.1 | Study procedures

Primary data for Deaf women in this study were gathered using the Health Information National Trends Survey in ASL, HINTS-ASL (Kushalnagar, Harris, Paludneviciene, & Hoglind, 2017) between November 2016 and April 2018. Secondary data for hearing women were drawn from NCI's HINTS 5 Cycle 1 survey (hints.cancer.gov) in 2017. For HINTS-ASL, the HINTS survey (hints.cancer.gov), which included items about cancer screening, was translated to and linguistically validated in ASL (HINTS-ASL). Following IRB approval, this HINTS-ASL survey was administered to Deaf adults in the United States. Only those who provided informed consent took the online survey in ASL. Hearing participants were recruited through random sampling whereas Deaf participants were recruited through purposive and snowball sampling, which have been reported to be effective for hard-to-reach populations.

This study focused exclusively on two survey items that were relevant to one's awareness of *BRCA 1/2* testing and knowledge. Since the same questions were asked of both groups, the Deaf women's responses could be compared to the responses of women from the general population. The following HINTS items were used in this study:

1. Awareness of genetic testing and BRCA 1/2 genetic test

- *"Doctors use DNA tests to analyze someone's DNA for health reasons. Have you heard or read about this type of genetic test?" (yes, no)*
- *"Have you ever had BRCA 1/2 testing?" (yes, no, don't know)*

> Participants who selected "yes" to the question on awareness of genetic testing also answered the question that asked if the participant had ever had a *BRCA 1/2* genetic test:

2. eHealth platform use

- *"In the past 12 months, have you used the Internet to look for health or medical information for yourself"? (yes, no)*
- *"In the past 12 months, have you used the Internet to look for health or medical information for someone else?" (yes, no)*
- *"Sometimes people use the Internet to connect with other people online through social networks like Facebook or Twitter. This is often called "social media." In the last 12 months, have you used the Internet for any of the following reasons?"*
  - o *"Visited a "social networking" site, such as "Facebook" or "LinkedIn" to read and share about medical topics" (yes, no)*
  - o *"Watched a health-related video on YouTube"? (yes, no)*

2.2 | Data analysis

First, chi-square analysis was used to investigate Deaf women's awareness of genetic testing by comparing the sample characteristics of Deaf women who had heard of genetic testing to Deaf women who had not. Age was grouped into five age categories (18–34, 35–49, 50–64, and 65+). Age-weighted chi-square analyses were then used to compare awareness of genetic testing, *BRCA 1/2* genetic testing, and eHealth platform use between Deaf and hearing women who had heard of genetic testing. The statistical program SPSS version 25.0 was used for all analyses.

3 | RESULTS

3.1 | Awareness of genetic testing among Deaf women

Table 1 describes the unweighted sociodemographic characteristics of Deaf women who answered all HINTS-ASL questions related to awareness of genetic testing (N = 325). Within this sample, 63% had heard of genetic testing and 37% had not. Deaf women who had heard of genetic testing were more likely to be young adults, college graduates, and/or have a family history of cancer. On the other hand, Deaf women who had not heard of genetic testing were more likely

TABLE 1 Unweighted sociodemographic characteristics of Deaf women who answered the DNA knowledge question in HINTS-ASL (N = 325)[a]

Subgroups	Never heard of DNA tests n = 120 n	%	Heard of DNA tests n = 205 n	%	χ^2 (p-value)
Age group					
18–34	25	20.8	74	36.1	29.92* (<0.001)
35–49	19	15.8	53	25.9	
50–64	36	30.0	48	23.4	
65+	40	33.3	30	14.7	
Race					
Non-Hispanic White	88	73.3	155	76.4	7.99* (<0.05)
Non-Hispanic Black	14	11.7	9	4.4	
Hispanic	13	10.8	21	10.3	
Other	5	4.2	18	8.9	
Education					
High school	46	39.3	23	11.5	38.84* (<0.001)
Some college	25	21.4	36	18.0	
College	46	39.3	141	70.5	
Preferred language					
ASL	60	51.7	77	37.7	12.68* (<0.01)
English	5	4.3	34	16.7	
Both ASL and English	51	44.0	93	45.6	
Family history of cancer					
None	28	23.7	32	16.1	9.62* (<0.01)
Have history	80	67.8	162	81.4	
Not sure	10	8.5	5	2.5	
Personal history of cancer					
None	94	79.7	153	75.0	0.91 (0.34)
Have or had cancer	24	20.3	51	25.0	

[a]Percentages are determined by total number of responses (n) to each question.
*denotes significance.

TABLE 2 Age-weighted sociodemographic characteristics and cancer history of Deaf and hearing women who answered "yes" to heard of genetic testing question in HINTS-ASL and HINTS

Subgroups	Deaf (%)	Hearing (%)	χ^2 (p-value)
Age group			
18–34	26.5	15.4	42.03* (<0.001)
35–49	34.5	23.2	
50–64	28.0	33.5	
65+	11.0	27.9	
Race			
White	78.2	67.7	20.90* (<0.001)
Black	3.0	13.9	
Hispanic	9.6	10.8	
Asian	5.1	3.1	
Other	4.1	4.6	
Education			
High school	11.8	24.7	30.52* (<0.001)
Some college	14.9	23.1	
College	73.3	52.2	
Family history of cancer			
None	15.4	19.4	2.27 (0.32)
Have history	82.1	77.2	
Not sure	2.6	3.4	
Personal history of cancer			
None	74.4	84.1	11.16* (<0.001)
Have or had cancer	25.6	15.9	
No	80.5	92.6	59.69* (<0.001)
Yes	15.5	7.4	
Don't know	4.0	0.0	

*denotes significance.

to self-report a preference for communication in ASL and self-identify African American. There was no significant difference in awareness of genetic testing between participants who had a personal history of cancer and those who did not.

The characteristics of Deaf women aware of genetic testing were then compared with their hearing peers. Table 2 is weighted by age and describes the characteristics of Deaf (n = 205) and hearing women (n = 1,088) who answered "yes" to heard of genetic testing question in HINTS-ASL and HINTS. There was an age-related difference between hearing and Deaf women who reported having heard of genetic testing. Deaf middle-aged women (35 to 49 years old) were the most likely to have heard of genetic testing, whereas older hearing women aged 50 to 64 years old displayed the greatest awareness of genetic testing (χ^2 = 42.03, p < 0.001). The racial disparity for awareness of genetic testing was significantly higher among Deaf women compared to their hearing peers (χ^2 = 20.90, p < 0.001). Hearing women without a college degree were more likely to have heard of genetic testing in comparison to Deaf women without a college degree (χ^2 = 30.52, p < 0.001). Having a family history of cancer did not differ across hearing status. However, hearing women who had cancer themselves were more likely to have heard of genetic testing compared to Deaf women who had cancer (χ^2 = 11.16, p < 0.001).

3.2 | BRCA 1/2 genetic testing

Respondents who said they had heard of genetic testing (n = 1,272; age-weighted) were asked a second, more specific question about whether they had had *BRCA 1/2* testing. Using

age-weighted data, Table 2 shows that 15.5% of Deaf women and 7.4% of hearing women reported they had been tested for pathogenic variants in the *BRCA 1/2* genes. In the same sample, 4% of Deaf participants did not know if they had had *BRCA 1/2* genetic testing, whereas none of the hearing participants reported this uncertainty. Overall, both groups were similar for family history of cancer among those who were tested for pathogenic variants in *BRCA 1/2* genes. Of those who had had *BRCA 1/2* genetic testing, 60% of Deaf women reported a personal history of cancer while only 26% of hearing women reported a personal history of cancer.

3.3 | Use of eHealth platforms

Table 3 describes the use of eHealth platforms (i.e. Internet and social media sites) by Deaf and hearing women who answered "yes" to the genetic testing awareness question. Compared to hearing women, Deaf women who had heard of genetic testing were more likely to have used the Internet to retrieve health or medical information for themselves (χ^2 = 10.75, p=0.001) and for someone else (χ^2 = 10.16, p = 0.001). Furthermore, more Deaf women than hearing women reported using social networking sites to read or share information about medical topics (χ^2 = 94.92, p < 0.001). Deaf women were also more likely to watch health-related videos on YouTube compared to hearing women (χ^2 = 37.27, p < 0.001).

4 | DISCUSSION

To our knowledge, this is the first study to investigate awareness of genetic testing and *BRCA 1/2* testing in a national sample of Deaf women. In Boudreault et al.'s study (2018) with data from November 2013 to March 2014, none of the 12 participants in the focus group could define the term "*BRCA1*". Since 2013–2014, there does seem to be an increase in the awareness of genetic testing among Deaf women who participated in the current study.

TABLE 3 Age-weighted eHealth platform use by Deaf and hearing women who answered "yes" to heard of genetic testing question in HINTS-ASL and HINTS

	Deaf (%)	Hearing (%)	χ^2 (p-value)
Usage of the Internet for health or medical information for oneself			
No	7.6%	19.9%	10.75* (0.001)
Yes	92.4%	80.1%	
Usage of the Internet for health or medical information for someone else			
No	16.7%	30.6%	10.16* (0.001)
Yes	83.3%	69.4%	
Usage of social networking sites to read or share about medical topics			
No	49.0%	81.3%	94.92* (0.001)
Yes	51.0%	18.7%	
Usage of the Internet to watch a health-related video on YouTube			
No	42.6%	68.1%	37.27* (0.001)
Yes	57.4%	31.9%	

*denotes significance.

Compared to Boudreault et al., Deaf female participants in this study demonstrated greater overall awareness of *BRCA 1/2* and genetic testing. However, it is important to note that Boudreault et al.'s sample was a focus group with 12 female participants whereas our study includes a larger sample of the Deaf population. Although these methodological differences are present, there have also been multiple changes in the environment that have likely contributed to an increased knowledge of genetic testing related to breast cancer. One likely significant contributor is the growth in advertising for direct-to-consumer (DTC) genetic testing and the promotion of those services through eHealth platforms and direct to consumer mailing advertisements. Recent research shows that Deaf individuals access the Internet for health information, making the advent of DTC genetic testing a possible contributor to the improvement of Deaf women's awareness of genetic testing (Kushalnagar & Kushalnagar, 2018).

Another factor that may influence the increase in the awareness of genetic testing is the circulation of health information in ASL among members of the Deaf community. Community-focused, breast cancer education efforts have been documented in the scientific literature since the 1990s (Boudreault et al., 2018; Firl, Morris, & Kish, 2019; Palmer et al., 2017), and such efforts have helped increase the community's overall knowledge, thereby highlighting the value of community-focused health education programs.

Simultaneously, the rapidly expanding use of evolving electronic and eHealth platforms has further facilitated the sharing of information. Social media platforms that offer video features, such as Facebook and Instagram, and free online meeting applications, such as appear.in and zoom.com, have increased the ease of sharing health information face-to-face. Those innovations have particularly benefited the Deaf community's members who heavily rely upon ASL, which is a visual language and does not have a written component.

Websites of official, trusted cancer-aligned and other health organizations have engaged in efforts to educate the Deaf community about cancer through videos in ASL (Firl et al., 2019). In particular, YouTube has offered an equally powerful venue for increasing Deaf women's access to health knowledge. As a free resource and mostly accessible platform, Deaf individuals can access YouTube videos at any time, as well as add subtitles/captioning to most videos (if they do not already include them). As with most health information online, information provided in YouTube videos about genetic testing and diseases must be viewed with caution. Since platforms like YouTube are free and public, any individual can post health and cancer information without any prior "fact-checking," expertise, or credentials.

Although the increase in Deaf participants' awareness of genetic testing is promising from this study, it is still important to recognize that a large portion of the study's participants did not demonstrate possession of the critical knowledge that is the focus of this study. As the community's awareness of genetic testing increases, increased cancer screening is likely to follow as women begin to understand the

implications of genetic testing. In the study, there was a greater tendency for hearing women without a personal history of cancer to still undergo *BRCA 1/2* testing, whereas the reverse was the case for Deaf women. A majority of Deaf women who had *BRCA 1/2* testing already had a personal history of cancer, suggesting that Deaf women might not be using genetic testing to help identify whether they are at increased risk for breast and ovarian cancer early on, before they were diagnosed with cancer. The missed opportunity to be tested might be due to inaccessible communication in healthcare, low health literacy, or simply not discussed as a recommendation by their doctors.

4.1 | Practice implications and research recommendations

Currently, there are widespread efforts to make eHealth platforms accessible for Deaf individuals. To help increase access to genetic information, eHealth platforms should be accessible in ASL and use text that is below a sixth-grade reading level while still retaining the original content of the health information (Boudreault et al., 2018; Kushalnagar et al., 2016). These modifications have been shown to significantly improve Deaf individuals' understanding of health information.

In the study, level of education was significantly associated with participants' awareness of genetic testing. This highlights the need to assure that Deaf high school and college students receive a strong foundation in health and science that will enable them to continue to expand their knowledge in those areas throughout their lifetime. It is also critical to increase Deaf youth's health literacy so that they know to ask their parents or guardians about their family health history. If a family member has/had been diagnosed with breast cancer, his/her family members may also be vulnerable to this disease, especially if the susceptibility to the disease is hereditary.

Although the majority of Deaf women with a family history of cancer had heard of genetic testing in this study, there were still a number of Deaf women with a family history of cancer who had not heard of it. When comparing the Deaf and hearing groups, substantially more hearing women were unsure if they had a family history of cancer in comparison to their Deaf counterparts. It is possible that awareness of family history of conditions is greater in the Deaf community, where it is estimated that 10% of Deaf children have an inherited susceptibility to develop Deafness. Thus, Deaf people may better understand the imperative to share family cancer and health history with one's children and later generations so that they can be fully knowledgeable of not only their health history but also any health risks they may have. As shown in this sample, not all women with a family history of, and potential vulnerability to, cancer are utilizing genetic testing as a measure to help reduce their risk of developing breast or other types of cancer.

This study showed that in the Deaf sample, as age increased, awareness of genetic testing decreased. This trend is likely to be related to the recent finding that younger Deaf adults utilize the Internet more often than older Deaf adults (Kushalnagar & Kushalnagar, 2018). It is possible that these young Deaf adults acquired awareness to genetic testing through the Internet. Given Deaf individuals' potential difficulty accessing information above the sixth-grade level, clinicians should be more active in educating their Deaf patients in an accessible manner. They should ensure that their Deaf patients understand the implications of a pathogenic variant in *BRCA 1/2*, the role it plays in increasing a woman's risk for breast cancer, and the potential benefits of genetic testing, including more focused early detection efforts (Easton et al., 2015). Equally important, with older Deaf women demonstrating a disproportionately lower level of breast cancer knowledge and awareness of genetic testing, special emphasis needs to be given to older Deaf women since older women are at the greatest risk of developing breast cancer and are less likely to be armed with optimal genetic screening-related knowledge.

4.2 | Study limitations

Our study has some limitations. Purposive and snowball sampling methods were used to recruit Deaf participants. However, these methods also captured Deaf women who were unlikely to otherwise join a research study. The survey items also did not inquire which YouTube videos or social networking sites Deaf women used for health-related purposes. Strengths of the study include a national representation of Deaf participants who come from diverse racial and ethnic groups, and survey items come from a robust multistage ASL translation process, a translation testing group of respondents with a range of educational achievement levels, and Deaf research staff. In general, among women, there is still an insufficient understanding of genetic mutations as well as preventative and early detection measures against breast cancer. It is critical that eHealth platforms for genetic testing and counseling are accessible for all, including simplified text and videos in ASL for Deaf consumers.

AUTHOR CONTRIBUTIONS

PK designed the research, gathered data, analyzed the data, and wrote the paper; JH conducted a review of the literature and wrote the paper; GS provided intellectual content and wrote the paper; PK had primary responsibility for the final content. All authors read and approved the final manuscript.

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COMPLIANCE WITH ETHICAL STANDARDS

Conflict of interest

Poorna Kushalnagar, Juliana Holcomb, and Georgia Robins Sadler declare that they have no conflicts of interest.

Human studies and informed consent

All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000 (5). Informed consent was obtained from Deaf and hard of hearing participants who took HINTS-ASL survey. Secondary data drawn from HINTS public datasets were exempt from IRB review.

Animal studies

No nonhuman animal studies were carried out by the authors for this study.

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