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Joint Bilingual Navigation of Informed Consent and Intake Forms in American Sign Language and Written English

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Abstract

People who are Deaf or Hard of Hearing (DHH) experience significant health disparities primarily due to barriers in communication accessibility. Approximately 500,000 individuals in the United States primarily use American Sign Language (ASL) and frequently encounter difficulties with informed consent or intake forms that are presented exclusively in written English rather than their native language. Recent advancements in machine learning for Individual Sign Language Recognition (ISLR)—the translation of individual ASL signs—provide an opportunity to develop fully bilingual forms in both ASL and written English. These bilingual forms have significant potential in healthcare and employment contexts, ensuring comprehensive accessibility for Deaf signers fluent in ASL and hearing intake personnel fluent in English.

We propose the concept of "joint bilingual navigation," which allows users to interact with digital forms either by signing into a camera-equipped device or through touchscreen interaction with written English. In this paper, we evaluate a bilingual informed consent and intake form that simultaneously supports navigation via natural ASL signs and traditional touchscreen input. Our user studies assessed interest and usability among Deaf signers and hearing non-signing intake staff, particularly focusing on obtaining informed consent and signatures from Deaf participants. The results indicate that such bilingual approaches are effective and positively received. These findings have broader implications, demonstrating that similar bilingual navigation techniques can be applied effectively in other domains requiring inclusive and accessible interactions.

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Keywords

Deaf and Hard of Hearing; Machine Learning; Informed Consent; Sign Language Recognition; American Sign Language

1 INTRODUCTION

People who are Deaf or Hard of Hearing (DHH) constitute a substantial minority within the American population, with approximately 11 million individuals identifying as DHH or experiencing significant hearing difficulties[10]. The National Institute on Deafness and Other Communication Disorders estimates that 37.5 million Americans have some degree of hearing loss[37], including at least 500,000 people who primarily use American Sign Language (ASL) as their main form of communication[31]. DHH individuals are underrepresented in healthcare and employment, largely due to inaccessible recruitment and data collection methods, including challenges in the informed consent or intake form process. Consequently, DHH individuals often experience disparities in healthcare and employment outcomes[4].

Improving participation of DHH individuals in healthcare or employment can facilitate inclusion in that consider accessibility needs. A critical barrier to inclusion arises during the informed consent or intake stage, where documents are typically provided only in written English, which is a second language for many DHH individuals who primarily communicate using ASL. Translating these documents into ASL could greatly enhance comprehension and participation among DHH populations.

Recent advances in artificial intelligence and machine learning have created opportunities in sign language recognition technology, particularly Individual Sign Language Recognition (ISLR) [43]. Although this technology is still developing, exploring its application in human-computer interaction (HCI) is vital, especially in addressing accessibility challenges faced by the DHH community. Current digital informed consent processes and intake forms often integrate sign language videos but still require interaction through written English, limiting true accessibility. There has been recent work that has been done on creating both digital informed consent processes and survey systems that use sign language videos instead of written text with the goal of making them sign language-accessible. For example, researchers have translated the Health Information National Trends Survey (HINTS), which is available in both English and Spanish, into an ASL-accessible format by integrating sign language videos [26]. They have been successful in translating the English and text-based content of informed consent processes and intake forms into content that is accessible to DHH participants, but this does not yet mean that the entire system is fully sign language-accessible. When DHH users interact with these digital informed consent or intake processes, the content may be in sign language, but they are still required to switch modalities to interact with the form through text interaction. Navigation of both types of systems is through pressing buttons to navigate forward and backward through these forms, rather than through sign language.

To address these limitations, we developed a joint bilingual interactive form designed for informed consent processes that translates written English content into ASL and allows navigation entirely through ASL via sign language recognition technology. This approach removes the need for users to switch between languages, significantly improving comprehension and accessibility. Additionally, the application simultaneously provides written English navigation to support English-speaking hearing researchers or investigators overseeing the consent process. Our goal is to enhance inclusion and ensure equitable participation of DHH individuals in healthcare research and beyond.

Our paper presents two major contributions:

1. We present a prototype that displays the form in both ASL, navigable by using individual sign recognition user interface, and simultaneously in written English, using text-based user interface.
2. We gathered quantitative and qualitative feedback from both PIs who run research studies and DHH individuals who may be interested in joining these research studies in the future.

2 RELATED WORK

This section summarizes the literature relevant to our study. We begin by reviewing current standards for informed consent forms and their limitations in meeting the needs of Deaf or Hard of Hearing (DHH) individuals. We then examine advancements in sign language recognition at the intersection of artificial intelligence and accessibility. Lastly, we explore existing efforts to create accessible forms and surveys, highlighting current gaps that our research seeks to address.

2.1 Informed Consent and Intake Accessibility Challenges

In the United States, when healthcare participants primarily use a language other than English, informed consent or intake documents must typically be translated into their primary language. Additionally, spoken language interpreters may be required to facilitate the informed consent or intake process, and are often available over the phone. Federal regulations mandate that informed consent be provided in a language understandable to the participant (45 CFR 46.116) [35] or the Civil Rights Act of 1964[3]. For DHH participants, American Sign Language (ASL) interpreters are often unavailable due to various logistical and scheduling challenges, such as cost or limited availability.

This lack of access poses significant barriers for Deaf or Hard of Hearing (DHH) participants, many of whom experience lower literacy levels in written English compared to hearing peers[16]. This disparity largely stems from language deprivation, a result of limited exposure to ASL during critical developmental periods[18]. Furthermore, informed consent or intake forms frequently contain complex terminology and jargon, which complicates comprehension for DHH individuals[40]. However, hearing non-signers cannot follow the signed content. As a result, providing accessible and fully bilingual consent materials in both ASL and written English is essential to improving participation and equity in research involving the DHH community.

2.2 Word-Level Sign Language Recognition

Sign language recognition, analogous to speech recognition, is a critical technology underpinning capabilities such as sign-to-text (translating signs from languages like American Sign Language to English text), sign-to-sign, and text-to-sign translation. Sign language recognition typically falls into two categories: word-level and sentence-level recognition. Word-level recognition involves using machine learning methods to translate individual signs independently, without considering the surrounding context. Over the past five years, significant progress has been made in word-level recognition using predominantly computer vision-based approaches. These include methods that rely on RGB input [28], skeleton landmarks [7], or skeleton heatmaps [14]. More recently, researchers have developed linguistically informed approaches to word-level sign recognition, which have demonstrated modest improvements [24]. Nevertheless, as highlighted by recent reviews, sign language recognition research faces two primary challenges: the shortage of adequate datasets and the absence of standardized metrics for evaluating system robustness [8]. While word-level recognition alone is insufficient for comprehensive and robust sign language translation, it is highly suitable for scenarios requiring recognition of a limited set of individual signs. One such application is sign language-based navigation and form control, as demonstrated by the form discussed in this paper.

2.3 Speech and Gesture-based Navigation

In exploring sign language-based navigation, we first reviewed existing research on natural language-based navigation more broadly. Significant research has been conducted in spoken language, particularly focusing on speech recognition for application control, text entry, speech analysis, conversational agents, spoken output, and related areas [21]. Additionally, previous studies on voice-based navigation have evaluated its effectiveness for navigating complex web-based menus and interfaces [22]. However, there appears to be limited research specifically addressing navigation in sequential, content-driven systems.

Gesture-based navigation research has primarily focused on non-traditional interfaces and technologies. Examples include navigation using wearable devices [33], interaction with applications like Google Earth [39], volume control [34], and robotic control [11, 15]. One investigated gesture-based navigation for web browsing, specifically evaluating gestures for issuing back and forward commands [32]. While this study did not specifically address sign language systems or Deaf and Hard of Hearing (DHH) users, it found that participants navigated significantly faster using gestures compared to traditional methods, and participants expressed positive attitudes toward the gesture-based approach.

2.4 Community Based Participatory Research

In conducting this research, we follow a Community Based Participatory Research (CBPR) paradigm. CBPR is an approach to research that aims to reduce health disparities by creating an equitable process that involves professionals and participants from the community [12]. Several works have been published that focus on the benefits of CBPR [12], including many works focusing on improving the health of specific communities, such as those in developing countries [23], communities with diseases [38], communities with developmental disabilities [29] and the DHH community [30]. One particular paper investigated a CBPR approach to adapting survey items to ASL for DHH viewers [17], however users cannot respond to survey questions using ASL, they must read and select English text. The research in our paper aims to improve health outcomes for the DHH community in the United States by allowing them to understand more and participate more effectively, through the use of these accessible forms. Unfortunately, although DHH sign language users make up about 0.5% of the population in America [10], they are often not underrepresented in healthcare settings [27], and we hope that developing accessible informed consent or form will help increase DHH representation in healthcare or employment.

2.5 Design of Sign Language Video Content Interfaces

Previous research has explored the potential of creating accessible informed consent forms navigable through sign language. Tran et al. [42] and Hassan et al. [19] investigated sign language user interfaces for IPAs and smart phones, and results show that DHH users enjoy interacting with intelligent systems using sign.

Specifically, some additional foundational work has been conducted by Kosa et al.[25], who developed an accessible informed consent form for iPhone that users could interact with using American Sign Language (ASL). This form was capable of recognizing a limited set of signs, such as “YES” and “BACK.” When tested against a conventional navigation approach, the joint bilingual form demonstrated some usability limitations; for example, participants disliked the interruption of their workflow caused by small videos opening in full screen and requiring manual closing to continue using the app.

Tolossa et al.[41] built upon Kosa et al.’s work by optimizing the form for the larger screen of an iPad, thus enhancing the design flexibility and user experience. Although prior research indicated promise, users found the small screen of the iPhone restrictive, especially since exiting videos required pressing an “X,” disrupting the user’s workflow. The larger interface of the iPad helped address this issue, significantly improving user interaction.

However, despite these improvements, both implementations operated within a limited domain, recognizing only basic signs such as “YES” and “BACK.” While these efforts advanced accessibility in informed consent procedures, further research is needed to expand the scope and address user interface challenges comprehensively.

3 RESEARCH QUESTIONS

Our analysis of prior work revealed that the standard informed consent or intake forms do not satisfy all DHH needs, particularly for native ASL signers who prefer to communicate primarily through ASL. Prior work also revealed that developing an application that translates the English text of informed consent into ASL, while utilizing word-level sentence recognition to allow participants to navigate the form entirely using ASL, is a potential solution but needs further investigation. Furthermore, prior work has not involved hearing intake non-signers in the process. Thus, our research questions are as follows:

1. **RQ1:** Do intake non-signers, as well as DHH signers, find the accessible joint bilingual form *usable*, and how can future iterations of the form be improved?

2. **RQ2:** Are intake non-signers, as well as DHH participants, interested in using this accessible application in practice in the future?

The rest of our paper describes two studies that we conducted in order to answer these questions. Both studies were IRB-approved. Our first study (**Study 1**) focused on testing our joint bilingual informed consent / intake form and collecting feedback from hearing non-signers as well as some DHH participants. We conducted a follow-up study which involves a new iteration of the form with some updates and further testing with more DHH participants (**Study 2**). For both Study 1 and Study 2, our first research question (RQ1) will be answered primarily through quantitative analysis of System Usability Scale (SUS) scores [9] and our second research question (RQ2) will be answered primarily through qualitative analysis of feedback obtained from our participants.

4 STUDY 1: DEVELOPMENT

Kosa et al. developed an initial version of this ASL interactive form for the iPhone and tested it with remote participants for accessibility [25]. Tolossa et al. used the feedback from Kosa's project to improve the technology, including adapting the interactive form for the iPad and providing live sentence-by-sentence transcription of the content signed in the informed consent videos [41].

We improved the form by adding synchronized English content along with the signed ASL conent. We also clarified the onboarding section by adding more details and adding an eye icon that clarifies when participants are allowed to exit the current section of the form and proceed to the next section (see Subsection 4.2 for more details).

This form allows a sign language user to navigate through the application completely using ASL. This iteration was developed for use on iPads; our next iteration discussed in Section 7 can be used on the web. This application was developed using ResearchKit and SwiftUI, and using AppleML for the individual sign language recognition. We worked with hearing intake professionals to obtain their short-form [36] informed consent or intake forms to a team of translators at Gallaudet University, who translated the content into videos produced by a native ASL signer. The videos were uploaded into the iPad in advance, so they were ready to be shown to participants when needed. When a prospective DHH participant needs to complete the paperwork portion of the informed consent or intake process, they are asked to view the contents of the informed consent document in ASL on the iPad, alongside an English transcript. The application itself is divided into two parts: An onboarding section, and the contents of the informed consent document itself.

4.1 Onboarding Section

When the participants first open the app, there is an onboarding section that explains to participants how to use the application in both ASL and English. There are four videos to watch during the onboarding process, and the videos inform participants that:

1. They will be presented with a series of pages with videos that translate each section of the consent form into ASL, and that they must sign "YES" to agree to the current section and go to the next section.

2. There will be a transcript box on the screen with highlighted text that shows which part of the transcript is currently being signed.
3. There is a progress bar on the top of the screen with titles of each section, the sections that are complete will be marked with a dark colored background, and previously visited sections can be re-visited optionally by clicking on them or signing "BACK".
4. After concluding all sections, the participant will be asked to fully consent to the process.

4.2 Informed Consent Section

The informed consent and intake form has several components. There is a progress bar at the top of the screen that shows each section of the form (e.g. Introduction, Purpose, Procedure, etc.), allowing participants to track their progress. There is a large video taking up most of the middle-left of the form view, showing a person providing ASL translation of the content as well as an accompanying English transcript to the right of the video. The application also takes an .srt file as input to allow sentences in the English transcript to be highlighted in yellow, allowing participants to cross-reference which part of the English transcript is currently being signed by the ASL translator. This allows the intake specialists overseeing the forms to keep track of where the participant is in the document so that they may answer relevant questions, pause the document review to check for understanding, or add comments. All of these components can be seen by referencing Figure 1.

The informed consent/intake portion of our application includes several notable features. First, it supports limited-domain American Sign Language (ASL) recognition specifically for navigation. Participants can advance between sections by signing "YES" in ASL, indicating they understand the current content and are ready to proceed, analogous to initialing each section of a document. Participants may also sign "BACK" to return to the previous section or directly select any previously viewed section using the progress bar at the top of the screen.

To ensure accurate ASL recognition, a self-view camera is positioned at the bottom right of the screen. This allows participants to monitor their positioning and orientation relative to the iPad camera for clear capture of their signs.

Participants can control video playback to enhance accessibility and comprehension. Playback controls include adjustable speeds ranging from 0.25x to 2x, controlled by tapping the tortoise (slower) or hare (faster) icons at the bottom of the screen. They can also rewind or advance the video by five seconds or pause playback as needed.

A recent update introduced an "eye" icon located in the bottom right corner of the interpreter video. Initially, the eye icon remains closed during each new section, indicating that participants cannot immediately proceed. After a preset duration, designed to ensure adequate review of the content, the eye icon opens, signaling that participants can move forward. The timing for this feature can be customized as required. An illustration of this functionality is provided in Figure 1.

When the participant has finished the final section and reviewed everything, the application records them signing their consent in ASL, which is uploaded securely for the research team and serves as an equivalent to an English document with a written signature. Figure 2 shows an image of a DHH participant interacting with the form by signing “YES” to it. In contrast, in the background, another participant uses regular pen and paper for the informed consent process.

5 STUDY 1: METHODOLOGY

We tested our form with two groups—hearing healthcare intake professionals and DHH participants—in multiple venues. To clearly present our methods and procedures, we have divided the methodology section into subsections describing each experimental session.

5.1 Initial Testing at ABCT Conference

A two person research team from Gallaudet University went to the Association for Behavioral and Cognitive Therapies (ABCT) Conference in Seattle, Washington in November 2023. There, we demonstrated the form to healthcare professionals whose primary language was spoken English. We taught each participant how to sign “YES” and “BACK” in ASL and had them navigate through the form as though they were a participant. We collected their feedback using the System Usability Scale (SUS) and noted qualitative feedback obtained during debriefing conversations after the form demonstrations. Feedback from the professionals included the need for English text in the application alongside some indicator that the participant can proceed to the next section, as there is a time-lock before participants can move on to prevent rushing through the process. To that end, we added an English transcript and the eye icon as discussed in Section 4.2.

5.2 Follow-Up Testing at UMass

We brought this updated application to researchers at the University of Massachusetts Chan Medical School (UMass), where we demonstrated the application to a different cohort of healthcare professionals. From our research team, one researcher would act as the prospective DHH participant and the other oriented the researcher to the application. The UMass participants role-played as an healthcare intake professional walking through the form with a DHH participant. After this demonstration, a short conversation was recorded where the UMass participants shared their first impressions and feedback. These recordings were later transcribed and qualitatively analyzed for themes. Lastly, UMass professionals completed a survey that included questions about their current accommodation practices for prospective DHH participants, their current informed consent document translation protocols, and the SUS questionnaire. The SUS consists of 10 questions that are answered on a 5 point Likert scale ranging from “strongly disagree” to “strongly agree”. SUS scores range from 0 to 100 and the score is calculated using the formula developed by Brooke [9].

5.3 Testing with DHH Participants in Orlando, FL, Washington DC and Cleveland, OH

We tested with a wide variety of DHH participants in three different cities: Orlando, FL, Washington, DC, and Cleveland, OH. We showed them the form, taught them how to use it (including what signs the apps would recognize), and asked them to do a walk-through of the form while imagining they were a prospective patient. We attended and recruited participants from three Deaf events around the United States: the Deaf Seniors of America (DSA) conference in Orlando, the National Deaf People of Color (NPDC) conference in Washington DC, and an experimental session at the Cleveland Hearing and Speech Center (CHSC).

5.4 Participant Information

5.4.1 Hearing Participants. Hearing healthcare professionals were recruited through word-of-mouth and snowball sampling at both the ABCT conference and the University of Massachusetts. A total of 23 participants were recruited for this study; 7 from Seattle and 16 from UMass. We do not have in-depth demographic data for them.

5.4.2 DHH Participants. Study 1 analyzes results from 44 DHH participants: 14 participants from the Deaf Seniors of America (DSA) conference, 20 participants from the National Deaf People of Color (NPDC) conference, and 10 participants from the Cleveland Hearing and Speech Center (CHSC).

Of the 14 DSA participants, 11 were ages 65–74, 2 were ages 50–64, and one was age 35–49. Eleven had a college education and 3 had high school or less. Eight participants identifed as female, and 6 as male. Of the 20 NPDC participants, ages ranged from 23–61 with median 42. Eleven completed a college education, 7 had a postgraduate education, and 2 had some college education. Participants were evenly split between male and female, with 10 each.

Of the 20 NPDC participants, 15 said they used English “very well” while 5 said they used English “well”. Seven participants identified as Caucasian, 4 as African American, 1 as mixed African American and Caucasian, 1 as American Indian or Alaskan Native, 1 as Korean, 2 as Chinese, 1 as Filipino, 1 as a mix of many ethnicities, and 2 as Other.

Of the 10 CHSC participants, ages ranged from 31 to 65 with median 53. Two completed a college education, 2 had a postgraduate education, 5 had a high school education, and 1 had less than 8 years of school education. Six participants said they used English “very well”, 3 said “well” and 1 said “not well”. Eight participants identified as female, and 2 as male.

6 STUDY 1: RESULTS

6.1 Quantitative Results

6.1.1 SUS Scores. For the healthcare professional participants, the average SUS score for the 16 UMass participants was 91.25 (s = 9.35). According to Bangor et al. [6], a “passable” score is 70 or above and “truly superior” systems score 90 or above. For DHH participants, the average SUS score of the 14 DSA conference participants was 71.96 (s = 16.67). The average SUS scores of the 20 NDPC conference participants was 71.25 (s = 17.65). Finally, the average SUS scores of the 10 participants from the CHSC (Cleveland) was 69.75 (s = 22.68), for a combined total of 44 Deaf or Hard of Hearing participants. When considering all the DHH participants combined from all 3 groups (DSA, NDPC, and CHSC), it yielded an average SUS score of 71.14 (s = 18.37). A one-way ANOVA test was performed to compare the average SUS scores of the DHH participants from DSA, NDPC, and CHSC which resulted in a non-significant p-value of 0.9597. A t-test was performed to compare the average scores of DHH participants from DSA, NDPC, and CHSC to the hearing participants from the UMass study, resulting in a p-value of 0.0001 which indicates a significant difference. The SUS scores for hearing PIs were substantially higher when compared to SUS scores from the aggregated DHH participants. The SUS scores are represented visually by the bar chart in Figure 3.

6.1.2 Additional Survey Questions. Apart from the SUS, scores, healthcare professionals from both UMass and Seattle were asked to complete an additional survey with further questions aimed at finding out more about their own comfort level using the form and interacting with DHH participants as well as whether they had funding for and resources to assist DHH participants. Some of these questions were "yes" or "no" questions and the rest were answered on a 5 point Likert scale ranging from "not true at all" to "always true". An overview of some of the results for the multiple choice questions is provided below.

In our survey, one question asked the healthcare professionals on how comfortable they feel including DHH people who primarily communicate in sign language participate in their research. 31.2% of UMass participants indicated this is "always true" and 28.57% of Seattle participants indicated this is "always true". When asked if DHH participants who primarily used sign language were included in the studies performed by UMass and Seattle participants, 12.5% of UMass participants and 42.86% of Seattle participants answered "yes". Only 2 participants from UMass and 2 participants from Seattle indicated that they had involved an interpreter in the informed consent process for their DHH participants.

When asked if their institution or department had funding to support accessibility for research participants who need accommodations, only 14.28% of Seattle participants and 18.75% of UMass participants answered "always true". When asked whether their research projects were accessible to DHH people who primarily use sign language to communicate, 50% of UMass participants and 42.86% of Seattle participants answered "not true at all". When asked if a lack of resources limited their ability to make their research accessible to DHH participants who communicate in sign language, 50% of UMass participants and 57.14% of Seattle participants indicated that this is true about half the time or more.

Our survey also asked UMass and Seattle healthcare professionals about their feelings towards using the form in practice in the future. When asked whether they would be open to using the form as part of the informed consent and/or intake process in their research, 81.25% of UMass participants and 100% of Seattle participants responded "always true". When asked whether having access to the form would make them feel more comfortable about including DHH participants in their research, 93.75% of UMass participants and 85.71% of Seattle participants responded "always true".

6.2 Qualitative Results

6.2.1 Hearing Non-Signer Participants. Overall, UMass participants liked the joint bilingual form and commented positively on the app's ease of use and the concept of the form itself. UMass participants also mentioned that they felt the form was *"well thought out*", "*thorough*", and "*very impressive*". Some features that were noted by UMass participants as good features were the ability to control the speed of the delivery of information, the presentation of the navigation bar that contains each section of the informed consent process, and how the form prevents users from agreeing to each section of informed consent too early. Four UMass participants commented on the benefit of the sentence by sentence transcript highlighting, which allowed them to know what sentence was being signed at any given moment in the video.

In regards to the positive impact of the app, one UMass participant said "*it's definitely addressing a real need in healthcare*". Another participant mentioned how the form would allow healthcare professionals to be more "*socially connected*" with DHH participants. The form would give "*a greater level of confidence that the participant understood the information fully*" as well as "*reduce sampling bias*" and "*allow the inclusion of deaf and hard of hearing participants the opportunity to receive care that might not have been initially available due to lack of accessibility*".

Despite the majority of long-form feedback being positive, participants from UMass and Seattle had concerns about including the use of the form in their research. The main concern voiced by both UMass and Seattle participants was the cost of technology, including the cost of the tablet and form. There were 2 UMass participants who were concerned about how internet connectivity might impact the form. One Seattle participant commented that "*if it needs internet connection, that can be a barrier for people in remote areas*".

6.2.2 DHH Participants. DHH participants from the DSA and NDPC conference provided feedback based on their experience using the form. The overall sentiment was positive and many participants enjoyed using it. Four participants from NPDC described the form "*simple*", "*straightforward*" and "*user-friendly*", and therefore not needlessly complex. They thought the form was "*well-integrated with smooth transitions*". The overall feeling was that many were interested in use in future settings.

We obtained further DHH participant comments and feedback from the Cleveland cohort who were primarily group home users with low levels of English proficiency and varying levels of ASL proficiency. The CHSC participants' comments revolved around the themes of understandability and responsiveness. One participant commented "*I could visually understand the information in ASL.*". Another said *"I understood the explanations for the client rights easily and it clearly matched the paperwork."*, however one person noted to be cautious as many DHH participants come with various levels of literacy: *"It was easy to understand. But my experience is different from other people, not all Deaf will have an easy time understanding this depending on their background and abilities."*. Regarding responsiveness, some thought it was very smooth and one person said *"I thought this was really cool, really nice, really smooth"*. However, there was some feedback for potential improvements, for example one said "*It had a little problem with understanding YES, it also response when I did not even say anything.*" This was likely due to the person's involuntary movements being picked up by the camera.

Participants also thought the form was comfortable to use, quite enjoyable and had a positive outlook for the use of the form in practice in the future. One participant commented *"I really liked it. It was enjoyable to use. I found it to be a lot of fun. It talked about socializing with people and how to be helpful and it was all in sign over a video. That's a good way to get people involved to have a lot of fun so they can hear or see about what's going on. It was really interesting, a good way to make sure to get people feeling good, inspired, excited, socialized."* and *"Because you can see all the videos in sign language, it's very comfortable to use and was a positive experience to be able to learn about the client rights in ASL."*.

While participants generally enjoyed the form, they had some comments for potential improvements or things to consider. One person mentioned different dialects or variations in signs and to keep in mind some people might prefer specific sign variations, saying *"There were some variations that I think were regional. Um but I don't think are exactly the same, but, you know, that's just an idea to have more complimentary regional signs"*. Another mentioned "*It would be cool if there were visual options like dark mode, or Deaf-Blind/low vision friendly mode*".

7 STUDY 2: DEVELOPMENT

As mentioned in Section 3, we wanted to seek out more feedback from the DHH community so we conducted a follow-up study with an iterated version of the app, discussed in the next few sections.

7.0.1 Joint Bilingual Consent / Intake Form Development.

This version of the form iteratively improved the form that was discussed in Section 4. The main new features of this version are: (1) Creating a website-capable application with HTML, CSS, and JavaScript for use on browsers so they are usable on laptop and computers, as the previous version allowed only iPads and iPhones; (2) Updating the aesthetics of the application, a screenshot of the improved app is shown in Figure 4; and (3) Modifications to the limited sign language domain used (the previous version recognized the signs "YES" and "BACK" while this version recognizes the signs "YES", "NO", "AGAIN", and "CONSENT"). The sign "NO" allows participant to refuse to participate and exit, and the sign "BACK" was removed as many participants felt like using the user interface on the screen to manually change sections was more intuitive to use. The sign "AGAIN" allows the user to replay the current section, and "CONSENT" is a new addition to finalize the process with a virtual signature.

The sign language recognition model we used in the joint bilingual form consists of two components: A machine learning system based on Mediapipe's gesture recognition task guide for recognizing static handshapes and an algorithm for determining if a sign has been used. Mediapipe [2], developed by Google, is an open-source toolkit for Artificial Intelligence computer vision tasks. The gesture recognition task is built to recognize a static hand gesture in real time and can be trained with custom hand gestures using the Mediapipe Model Maker tool. The ASL Citizen Dataset [13] was used to obtain data for the required handshapes. The dataset consists of raw footage of participants signing in front of a laptop camera and contains 30 instances of the signs for "YES" and "NO" and 29 instances of “AGAIN” and “CONSENT.” These signs were manually screenshot at points where the handshape was clearly articulated. Due to the dynamic nature of the sign for “NO,” screenshots for “NO” were collected at both open and closed handshapes. The screenshots for “AGAIN” were also separated to mark the dominant and non-dominant hands. Each handshape screenshot was then mirrored to have data for both the left and right hands, and a gesture recognition task model was also trained using the Mediapipe model maker. The Mediapipe model runs client-side, within a browser on an individual’s device.As an added note, in this version, Mediapipe hand landmarks are also mapped onto the user’s hand to further assist with sign language recognition.

7.0.2 User Testing Set-Up.

The user testing set-up consisted of two laptops: one to host the ASL-based informed consent form for the participants to interact with and a second laptop that contained the combined demographic survey and ASL-translated System Usability Scale (SUS) [20].

8 STUDY 2: METHODOLOGY

We implemented a mixed-methods strategy for evaluating the usability and accessibility of our updated form, combining an experimental quantitative as well as a qualitative approach. This section outlines the study design, methods, and participant demographics.

8.1 Methods

Our deaf signer participants first gave consent to participate, then they were briefed on the purpose of the form and its use in providing equitable access to informed consent or intake forms. It was emphasized to each participant that the contents of the form shown was merely an example of what an ASL-informed consent or intake form might look like, and to allow participants to interact with them. The form we used for testing purposes in this experiment contained information about a proposed surgical procedure, including what it is and its effect on the body, as well as the purpose, benefits, risks, and costs of participating in it, among other relevant information.

The participants were also informed that their screens would be recorded and analyzed to improve future form iterations. After signing the video release form, the participants were instructed to navigate through the consent form. Similar to that of Study 1, they underwent an onboarding process that demonstrated the signs recognized by the form (YES, NO, AGAIN, and CONSENT) and their functions. Each participant was directed to watch all the videos of the consent form to completion.

After interacting with the app, participants were instructed to begin the questionnaire on the second laptop. After providing demographic information, the participants responded to the 10-question ASL-SUS. Afterwards, participants were asked to answer open-ended feedback questions through a video response. The screen and video recordings of each participant was coded in ELAN [1], a transcribing and annotating software, to take note of participant learner behaviors, technical problems, and the duration of form usage. Each participant action within the form was coded by annotating interactions (the action initiated) and comments (more details about what happened). For example, if a participant signed

"YES" to move to the next page, the interaction annotation would be *"Signing YES"* and the comment would include additional information such as whether the sign was successful and recognized by the system or not. Analyzing our recordings of participants also helped determine whether participants utilized various ways to interact with the app, such as clicking sections on the top navigation bar (The navigation bar at the top was hyperlinked to previous sections so participants could easily jump sections), or clicking the transcript to jump the video to a specific line in the transcript. All of the videos were transcribed by a hearing native ASL signer with assistance from a Deaf fluent signer. Both the open-ended feedback and ELAN annotations were analyzed through a open-coding process for themes.

8.2 Participant Information

A total of 10 DHH participants who use American Sign Language (ASL) as their primary language were recruited from posting fliers at Gallaudet University alongside word-of-mouth. The mean age of the participants was 30.70 years (SD = 15.09), and ages ranged from 19 to 69. Six participants identified as female and 4 as male. Seven identified as Deaf/deaf and 3 as Hard of Hearing. Six self-identified as Caucasian, 1 as Latinx, 1 as Black Caribbean, 1 as Black or African American, and 1 as Multiracial. Four self-described their English use as "good" and 6 as "very good." Their educational backgrounds ranged from high school diploma or GED (1), some college or no degree (2), bachelor's degree (6), and graduate or professional degree (1). All participants completed an intake form to ensure that they met the eligibility criteria. Each participant was compensated Amazon gift card worth 25 US dollars.

9 STUDY 2: RESULTS

9.1 Usability

Figure 5 shows the participant SUS scores and ages. The mean SUS score among all participants was 78.75 (SD = 12.09) which corresponds to a "Good" grade [5]. There was a slight negative correlation (r = −0.17) between SUS and age, indicating that a user's SUS score may decrease as age increases. Additionally, the participants responded to the adjective scale question developed by Bangor et al. to evaluate the meaning of individual SUS scores [5]. The adjective scale question, "Overall, I would rate the user-friendliness of this product," has seven possible responses, ranging from "Worst Imaginable" to "Best Imaginable". In response to this question, three gave "Good", six participants gave the rating "Excellent", and one gave "Best Imaginable", thus every one of our participants rated our form positively regarding user-friendliness.

9.2 Participant Interactions with the App

The average time to complete was 11.54 minutes (SD = 2.77), from 7.18 minutes to 15.11 minutes. During the process, "YES" was signed 110 times, "AGAIN" was signed five times, and "CONSENT" was signed 14 times. Unfortunately, the sign "NO" was not used during user testing as participants did not attempt to exit the process, and were not instructed to test it. This was an oversight and thus there is no data on "NO" signs, but "NO" is a necessary interaction for the real-world application of the interactive bilingual form so that participants are empowered to exit the consent process if they do not want to proceed.

We created a confusion matrix (see Table 1) to demonstrate the performed action versus the outcome action to analyze the accuracy of interactions with the sign language recognition technology. An example of a performed action done by participants would be a "YES" sign, the outcome action notes what actually happened; the possibilities are: (1) The system recognized the sign accurately as "YES", (2) It recognized a totally different sign, or (3) Did nothing altogether (labeled No action). The most accurate interaction was signing "YES", which was recognized 84% of the time. The sign "AGAIN" was recognized with 80% accuracy, and the sign "CONSENT" was only recognized 57% of the time. Some errors appeared to be caused by participants keeping their hands too close to their faces and fidgeting while watching the videos.

To investigate potential relationships between recognition accuracy, SUS scores, duration to complete the form, and age, a pairwise correlation matrix was constructed and results are shown in Table 2. A strong negative correlation between SUS and TIME ($r = -0.8562$), a moderate correlation between AGE and TIME ($r = 0.5296$), and a slight negative correlation between SUS and ACCURACY ($r = -0.3181$) were identified. Increasing the time taken to complete the consent form process is correlated with a decrease in SUS scores and an increase in age. Surprisingly, a higher SUS score is also correlated with a lower sign language recognition accuracy.

9.3 Qualitative Analysis

Four themes were identified when analyzing feedback transcripts: Bilingual Language Access, Model Sensitivity, Timing, and User Choice.

- **Bilingual Language Access:** Information provided in ASL should match that in English to avoid confusion, distraction, and frustration during the informed consent process. Information should be evenly matched in terms of concept, duration, and complexity. *"The ASL was great, but the transcript was too short and only had a few lines which did not match the ASL video as I was reading the transcript." (P10)* and *"I prefer having both ASL and English for full information access and if they don't match, I feel thrown off." (P10).*
- **Model Sensitivity:** The model used for the ASL navigation of the consent form must not be too sensitive as to catch a user's every move but still be sensitive enough to detect signs in a prompt and receptive manner. Users should be aware of the sensitivity threshold of the model. *"Some parts are good but if you have to scratch your ear, you cannot reach up to scratch or else the camera will catch it." (P1)* and *"I noticed that the YES and CONSENT signs did not work for the first time a few times and had to be repeated a second or third time." (P9).*
- **Timing:** For full informed consent, a user must comprehend and acknowledge all information present in a consent form, even if they skip part of the videos. The visual cues that demonstrate the model's readiness to recognize *signs should be adjusted to prevent users from passively interacting with the consent form. "The eye symbol is open but the person on the screen is still signing. Maybe you should allow the user to speed up the video." (P1).*

- **User Choice:** Users should be able to customize elements of the form to improve personal access. Users may prefer to watch both the ASL videos and read the transcript, watch only the ASL videos, or read only the transcript. The current configuration of the form reduces the autonomy of the user, forcing them to interact with the ASL videos to navigate to the next portion. *"Some will prefer not to watch the ASL video and just read the transcript only. Give a choice between reading the transcript and continuing or watching the video and continuing." (P10)* and *"I'd prefer to just read the transcript and then click yes to finish the section." (P4)*.

10 DISCUSSION

10.1 Discussion of RQ 1

Our first research question, RQ1, asked whether both hearing non-signers and DHH signers would find the joint bilingual form usable and navigable. The SUS scores from UMass and Seattle indicate that healthcare professionals find this application has excellent usability. The SUS scores from DHH participants at NDPC, DSA, and CHSC indicate they find the system usable, but further development is needed. The difference between the overall SUS scores for the healthcare professional participants, over 90, and the scores for the DHH participants, roughly 70 across the three cohorts of DHH participants, is expected as the researcher participants are only evaluating their ability to use the application as an onlooker. Their experience of the form was evaluating their ability to follow the content in English and manage the flow of information to the research participant. Conversely, the DHH participants were evaluating the content in ASL, the English transcript, the tools to navigate the app, and the novel sign language recognition technology. As SLR technology is still in early stages of development, it is expected DHH participants SUS scores would indicate the technology still needs improvement.

The SUS scores from the Cleveland Hearing and Speech Center were slightly lower than that of the DSA and NDPC SUS scores. Though the difference is not statistically significant, we observed that the participant sample from CHSC was comprised of more DHH individuals who had experienced language deprivation or possible developmental delays. These participants required significantly more explanation of the application, greater guidance during user testing, took longer to navigate the application, and required significant support from an ASL-fluent support person. Despite this, their feedback was positive overall and many reported feeling independent when navigating paperwork through the ASL-Consent app.

10.2 Discussion of RQ 2

Our second research question, RQ2, asked whether our participants would be interested in using this accessible application in practice in the future. Both the DHH participants and research-associated participants found this application accessible, making it the first ASL and English fully bilingually accessible application for informed consent documents. The excellent usability rating from researcher participants indicate they feel this form is usable for their purposes at it's current state of development and the majority of researcher participants would be open to using this application in their informed consent process. The majority of researcher participants also indicated that access to this application would increase the likelihood that DHH participants would be recruited for their research, increasing the likelihood of recuding barrriers to DHH participation in research trials.

The researchers felt that the bilingual form meant they would be able to make their research accessible to DHH participants, and the DHH users experienced greater access to the informed consent healthcare information. The most common feedback comment was on how easy the app was to use, with 50% of the feedback including this theme. Every participant who mentioned ease found the system easy to use, clear, and intuitive. For Study 2, the strong SUS scores obtained also indicates that our system is intuitive to use and is higher compared to the average score in prior works [41]. A strong negative correlation between SUS scores and time was found indicating that the longer it takes to complete the form, the lower the SUS scores tended to be, which intuitively makes sense as taking longer may indicate more frustration. There was a positive correlation between age and consent form completion, indicating that older participants may require a longer amount of time to figure out how to interact with the form. Finally, it was surprising to see a slight negative correlation between SUS scores and accuracy, meaning that higher SUS ratings were correlated with lower sign recognition accuracy. It's possible that even if signs were not captured accurately, the participant's overall experience with using the form was positive to overcome this limitation.

10.3 Our App and Accessible Employment

While the research presented in this paper was focused on informed consent in healthcare applications, our research can extend to other domains such as accessible employment in the workplace. There is typically a lot of paperwork invovled with employment, such as needing to sign forms from human resources at time of hire, or annual evaluation forms of employees, tax and income forms, and so on. These forms could be ported into our app to make it easier for companies to communicate contents of these forms with their DHH workers and for DHH employees to become more independent at the workplace. Additionally, this app could practically be modified to work with spoken languages, e.g. Spanish, to aid people who speak a non-English spoken language as their primary language. Such modifications could include switching out the ASL signer with a Spanish speaker and including a Spanish transcript.

11 LIMITATIONS

Our research has several limitations and opens up avenues for future work that we address in this section. For both Study 1 and 2, we recruited participants from three specific locations: Orlando, Cleveland, and DC (and Study 2 recruited only from DC). Future work would need to investigate opinions and feedback from DHH participants more broadly across the United States, including reaching out those people who might not normally go out of their way to attend DHH events and conferences, especially since there are regional and cultural differences in DHH communities across the country. Additionally, since many of our participants self-rated as having good English skills, future work in this field should test these forms on more users who self-identify as having poor English skills, to document better any differences in their experience navigating our prototypes.

As for the form prototype, future work could also include improving the form by increasing its signed language recognition capabilities in general, including increasing the number of vocabulary words recognized, the accuracy of the sign language recognition algorithm, and improving responsiveness. Finally, future work is needed in actual clinical settings in practice to test and observe more healthcare professionals and DHH patients using the form during a live informed consent process.

12 CONCLUSION

Our research study focused on creating a joint bilingual informed consent or intake form that displays both an ASL and written English version of the informed consent or intake procedure that is fully accessible for both DHH participants, and healthcare professionals. While some minor improvements were suggested, both deaf signers and hearing non-signing healthcare participants found this technology to be accessible, easy to use, and worth expanding. DHH signers want to use interactive and responsive sign language recognition technology to navigate through processes that have historically been subject to the barrier of relying on written English.

The development and testing of the ASL informed consent website application aims to ensure that informed consent processes are accessible to Deaf and Hard of Hearing individuals by providing information in their native language, ASL. By implementing features such as sign language recognition to navigate through the consent form, interactive user interface to improve participant experience and a streamlined onboarding process, this study has demonstrated the potential for the interactive joint bilingual form to bridge communication barriers in academic research and healthcare settings.

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CCS CONCEPTS

• Human-centered computing→Accessibility technologies; Empirical studies in accessibility; Accessibility systems and tools.

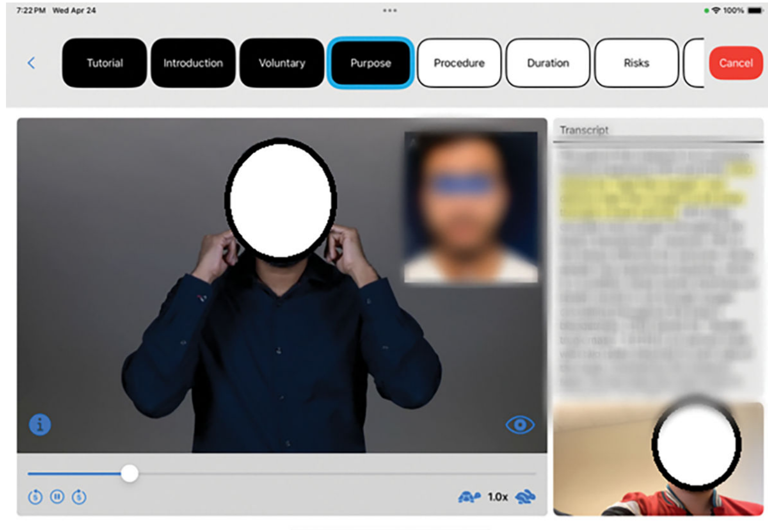

Figure 1:
A view of one section of the informed consent process on the application. There are several features available such as a progress bar on the top, a transcript to the right with highlighted text to show where the signer is at in the moment, as well as video playback controls.

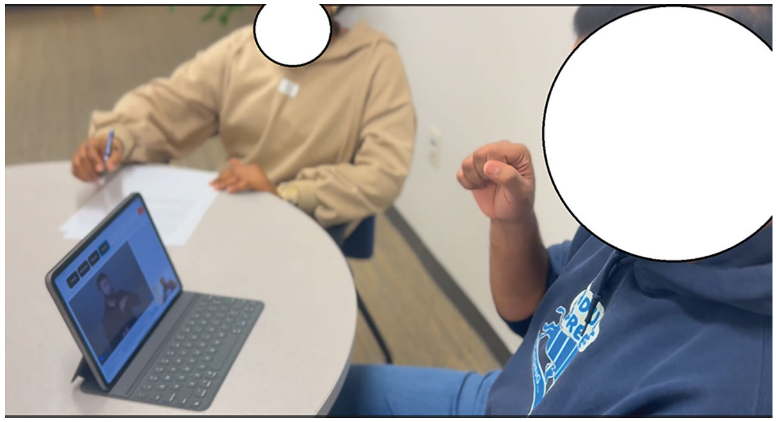

Figure 2:
This figure shows the contrast between two prospective participants who may choose different modalities for the informed consent process: The person in front is interacting with the form and the person in the back is using a traditional pen and paper approach.

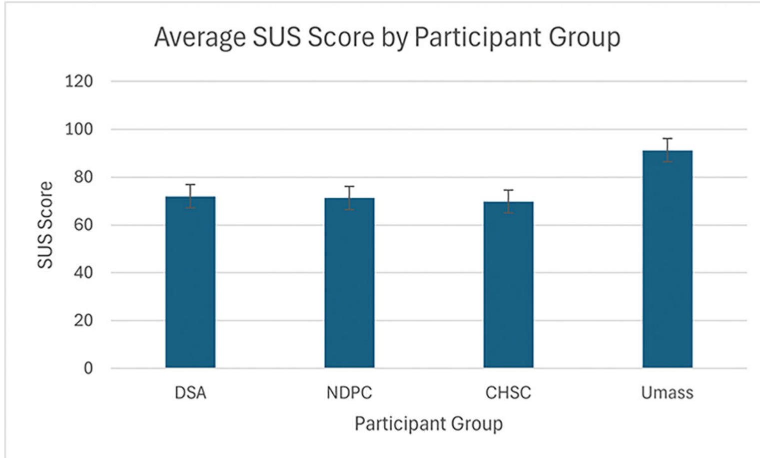

Figure 3:

This graph shows the average SUS scores by participant groups in each of the venues we conducted our experiments at. DSA, NPDC, and CHSC have DHH participants, and Umass has healthcare professional participants.

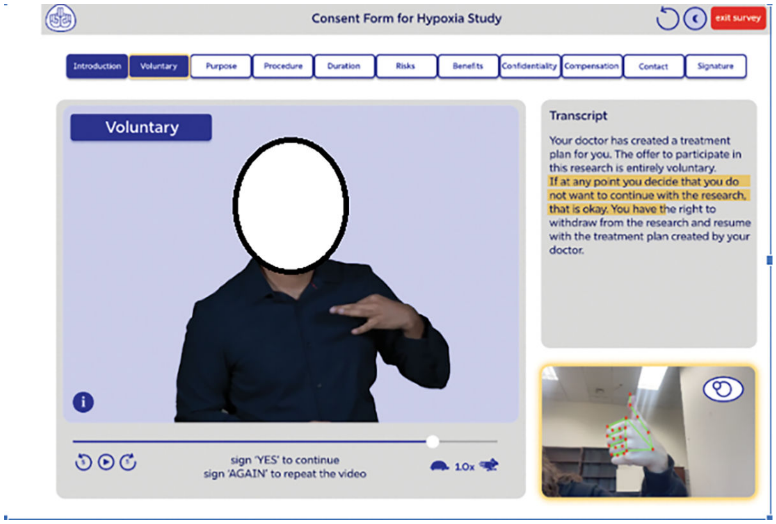

Figure 4:

A view of a later iteration of our informed consent application. Some features are kept because they were effective, but the aesthetics of the app have been improved and streamlined, and there are new features added such as a different sign language recognition model.

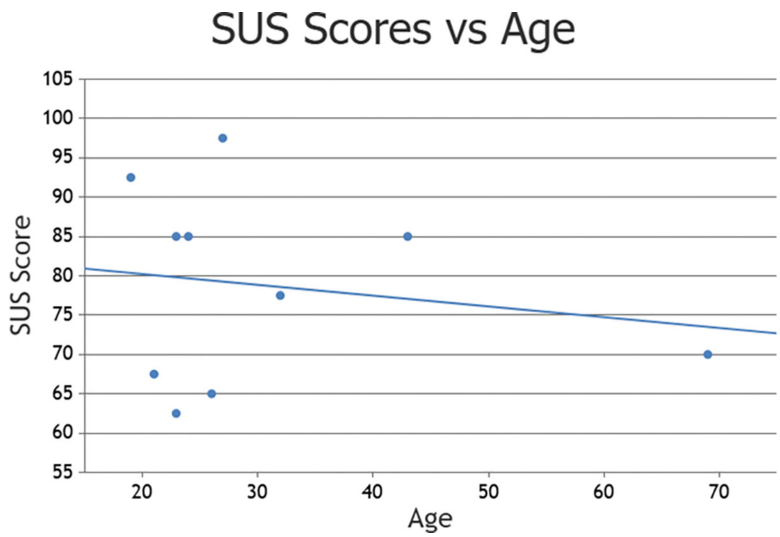

Figure 5:
A scatter plot showing SUS scores versus age.

Table 1:

Confusion Matrix for Sign Language Interactions (with percentages).

Performed	YES	NO	AGAIN	CONSENT	No action
YES	0.84	0.00	0.00	0.00	0.16
NO	0.00	0.00	0.00	0.00	0.00
AGAIN	0.00	0.00	0.80	0.00	0.20
CONSENT	0.00	0.00	0.00	0.57	0.43
No action	0.50	0.50	0.00	0.00	N/A

Table 2:

Pairwise correlation matrix of accuracy, SUS, time, and age.

	ACCURACY	SUS	TIME	AGE
ACCURACY	1	−0.3181	0.1457	−0.1565
SUS	−0.3181	1	−0.8562	−0.1713
TIME	0.1457	−0.8562	1	0.5296
AGE	−0.1565	−0.1713	0.5296	1