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Accessible Informed Consent Process in Interactive ASL Apps

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Abstract

Since informed consent became a mandatory measure in medical research, research participants have greater protections against research-related harm and exploitation. However, the information provided is often in written English. This creates a significant language barrier for deaf and hard of hearing people who use sign language as their primary means of communication. Additionally, hearing researchers, who make up the majority (NSF, 2017), are often less inclined to include deaf individuals in research due to the added work that is necessary to reduce the communication barrier between researchers and deaf participants. To address these issues, our research leveraged machine learning and artificial intelligence-based technology to test the usability of a user-centered and low-resource informed consent app-based toolkit. This toolkit allows researchers to easily provide interactive informed consent content entirely in American Sign Language. Building on the work of Kosa et al. (2023), we found that deaf people considered the app-based informed consent process to be accessible when completed entirely in ASL. This finding indicates the continued development of this technology would increase accessibility for the signing deaf community. This technology could be used by researchers to diversify their samples, improving the quality and broad applicability of the results of their research.

Keywords

Deaf and hard of hearing, machine learning, informed consent, American Sign Language, sign language recognition.

Introduction

This research tested technology that aims to reduce this communication barrier to create a more inclusive and accessible research environment for both Deaf individuals and researchers. By using machine learning models and artificial intelligence to capture and recognize sign language, we are able to provide a tablet-based application that uses American Sign Language (ASL) throughout the informed consent process. This application, the ASL Consent App, uses ASL videos to explain the informed consent process and participants are also able to respond using ASL. Before we presented the ASL-Consent App to participants, we made significant changes from the initial iteration of the Kosa et al. (2023) version of the application to improve usability.

To evaluate the overall usability of our ASL Consent App, we conducted two rounds of testing with Deaf and Hard of Hearing participants who used ASL (members of the Deaf community). The first round of participants were primarily senior citizens over the age of 65 whereas the second round of participants were primarily people of color with a diverse age range, but a majority were under 50 years old. Though the feedback from both groups was generally positive, their perception and expectations of the ASL Consent App differed. Senior citizens were sometimes unsure how to interact with the tablet in that they would center their bodies in front of the tablet instead of the camera or they would forget that the machine learning model only recognized a very specific set of signs. The feedback from the second round of participants indicated that they felt the app was easy to learn and easy to use, however some commented that those without experience with technology may require more user training which matched the experience of the senior citizens from the first round.

It was hypothesized that presenting the informed consent process in a culturally and linguistically appropriate manner for the signing deaf community would allow deaf individuals to have more autonomy as research participants as well as assist researchers in reducing the barriers that often prevent the deaf community from participating in research studies. The survey findings indicated this can be achieved through the development of accessible, application-based technology.

Deaf and Hard of Hearing Challenges in Understanding Consent

The Deaf community, comprised of deaf and hard of hearing sign language users, is a small population that is often at risk for marginalization (Sanfacon, Leffers, Miller, Stabbe, DeWindt, Wagner, & Kushalnagar, 2020; Kushalnagar, Reesman, Holcomb, & Ryan, 2019; Kushalnagar & Miller, 2019; NIH, 2022). Since English is often a second language for deaf ASL users, literacy is low and health literacy is also low due to the lack of accessible language (Anderson et. al. 2020). Informed consent in the signing deaf community is not achievable if the information is only provided in written English, a language that many deaf individuals consider their second language (Mckee et al. 2013). While the Deaf community is considered a population that experiences health disparities because of their disability status (Pérez-Stable 2023), they are not necessarily considered a vulnerable population requiring additional protections according to the National Institute of Health. To ensure deaf and hard-of-hearing sign language users are fully able to make decisions regarding informed consent, it is necessary to ensure equitable access to informed consent content in their primary language, ASL.

It is necessary to understand the importance of Community Based Participatory Research (CBPR) because developing assistive technologies for the Deaf community requires collaboration between researchers and Deaf individuals. The goal of CBPR is to both provide procedural information in accessible language as well as make clear that the research being performed is beneficial to the Deaf community (Singleton et al. 2014). Second, investigating Sign Language Recognition (SLR) technologies that are currently in development can provide a foundation to build upon further research (Papastratis et al. 2021). The work of Anderson et al. (2018) focused on how to provide social equality for Deaf participants in qualitative research. Accessible recruitment, sampling, data collection, and data analysis procedures must be utilized to conduct ethical and accurate research with the Deaf community. Data collection should be performed in the participants' primary language to reduce translation bias and increase translation accuracy. The study by Anderson et al. (2020) states that "the deaf community is one of the most understudied in the research community".

Sign Language Recognition

Sign Language Recognition (SLR) refers to the ability of machines to recognize sign language, which allows for Sign Language Translation (SLT): the ability for machines to translate from sign language to a spoken language, like English. Although meaning-to-meaning Sentence-Level SLT is not yet possible, recent breakthroughs in machine learning have made Individual Sign Language Recognition (ISLR) possible (Desai et al., 2023). One potential application of ISLR is what Kosa et al (2023) coins as Sign Language Interactability, which describes allowing users to interact with technology through sign language.

Allowing Deaf and Hard of Hearing participants who use ASL to navigate and sign the Informed Consent process may help make the process more user friendly. A preliminary study with a prototyped ASL Informed Consent Process using Sign Language Interactability in Kosa et al (2023) shows that Sign Language Interaction has great promise in doing this. However, the preliminary study had a limited sample size of 14 participants that did not reflect the diversity of the broader signing deaf community, a subpar user interface for their prototype, and an extremely limited user study procedure that took place over Zoom. Participants were only allowed to watch a recording of the app being used without being able to use it themselves, meaning responses from participants didn't fully reflect the usability of the app as their experience was indirect. One of the aims of this paper is to re-evaluate the usability of Sign Language Interactability in the ASL Informed Consent Process with an improved user interface.

Discussion

Development

In developing our ASL Informed Consent App, we based the core design on previous work done by our team (Kosa et al, 2023), but have iteratively made improvements to the user interface, features, and backend of the app. In the previous study, participants gave feedback that having the ASL informed consent process on an iPhone screen was too small. We incorporated this feedback into our current design by developing our ASL Consent App for the iPad. Participants also suggested the addition of an English transcript to supplement the ASL videos, which is consistent with previous work that evaluated how users prefer to view sign language videos (Willis et al., 2019).

Using the designs that these previous works developed, we incorporated the Multimodal Visual Languages User Interface (M3UI) into the design for our app, which found that users prefer to view sign language content alongside an English transcript that automatically highlights the English text in sync with the sign language that is being shown in the video. Participants in Kosa et al. also gave feedback regarding improvement in navigation feedback (e.g. breadcrumbs) and how it wasn't obvious how to use the novel ASL Interactability feature. We addressed the lack of navigation feedback by adding a sequential navigation bar that overviews every section in the informed consent process and shows what sections the participant has completed, which section they are on, and how many more they have left to do before they are done.

Participants sometimes had to ask for help during the middle of the ASL informed consent process because they weren't sure what to do next at the end of a section or how to navigate in ASL due to it being a novel concept. We addressed this issue in our current iteration of the ASL Consent App by adding an onboarding process that demonstrates how ASL Interactability works in the app. The previous iteration of the ASL Consent App in Kosa et al. had a separate section for signing the digital informed consent form that required the user to record themselves signing their full name, which would be stored in a secure database that could be viewed anytime as proof of signature. In their user study, Kosa et al. received feedback that participants found signing their full name felt clunky, and so at the end of our ASL Informed Consent process, the user only needs to sign "CONSENT" in ASL (which equates to "I Consent" in English) to provide their signature.

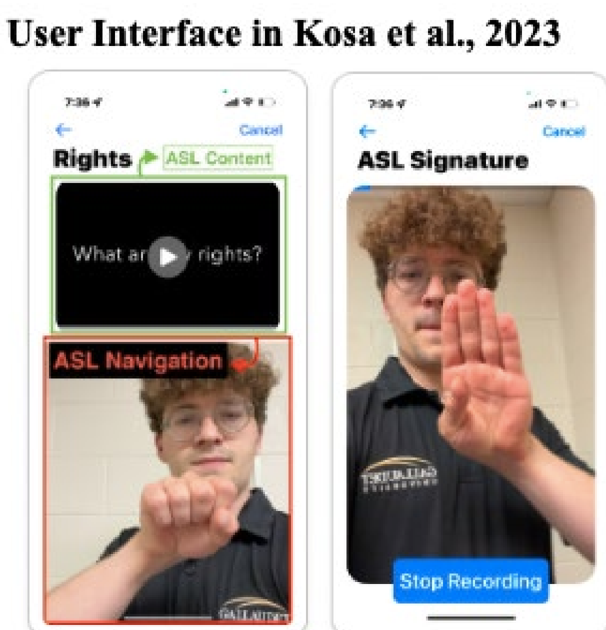

Fig. 1. ASL Informed Consent User Interface in Kosa et al., 2023.

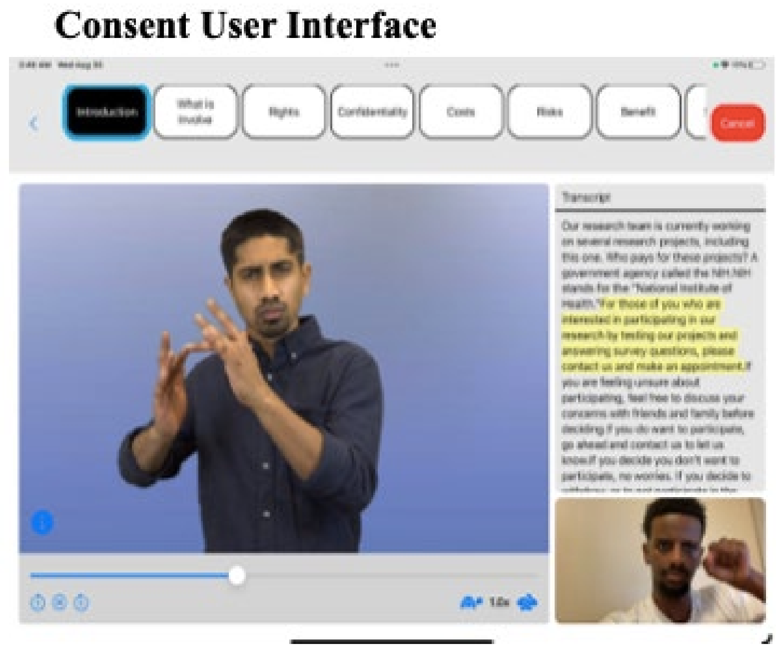

Fig. 2. Current ASL Informed Consent User Interface.

Method and Evaluation

All participants were deaf or hard-of-hearing fluent users of American Sign Language. The first round of participants was recruited from the Deaf Seniors of America (DSA) conference in Hollywood, Florida. The second round of participants were recruited from the National Deaf People of Color (NDPC) conference at Gallaudet University in Washington, D.C. Each participant worked with two iPads. We performed user testing using iPads that had the ASL consent app preloaded onto them. One iPad was used to collect informed consent, demographic information, and user feedback via a Qualtrics survey. The other iPad had the ASL consent app with which participants would interact with. Participants were given brief user training on how to use the application before user testing began. Participants were trained to avoid extraneous hand movements while using the app and to sign clearly when engaging with the receptive camera. Additionally, researchers found it necessary to explain to participants that while this application used artificial intelligence, they should consider the AI to be in its language-learning infancy.

This explanation alleviated concerns about the way artificial intelligence was being used and encouraged the participants to sign intentionally and clearly. Once briefed, participants would interact with the ASL consent app. After the participants completed testing the app, they then took the System Usability Survey (SUS) to collect feedback. The SUS consists of 10 questions that are answered using a Likert scale.

We learned from our experience with participants at the DSA that it may be helpful to include a video prompt for each section of the app to prompt the user to move forward or backward through the app by signing “Yes” or “Back”. We added this video prompting feature for the second round of testing at the NDPC conference. In addition to this, we added a text box and video recording option to the SUS survey so that participants could explain why they gave their rating for each SUS question. This allowed us to collect both quantitative and qualitative user feedback.

Results

Data was collected from a total of 34 participants, 14 participants from the DSA conference and 20 from the NDPC conference. Demographic data such as age and education level were collected. DSA participant ages ranged from 35-74 and NDPC participant ages ranged from 23-61 for an overall age range of 23-74. Education levels were sorted into the categories of high school or less, college graduate, and postgraduate. A table of demographic information for the DSA participants and NDPC participants is provided in Figure 3 and Figure 4, respectively.

Table 1. DSA Participant Demographic Data.

Participant	Age Group	Highest Degree Completed
P1	65-74	College Graduate
P2	65-74	High School or Less
P3	65-74	High School or Less

Participant	Age Group	Highest Degree Completed
P4	65-74	High School or Less
P5	65-74	College Graduate
P6	50-64	College Graduate
P7	65-74	College Graduate
P8	65-74	College Graduate
P9	65-74	College Graduate
P10	50-64	College Graduate
P11	65-74	College Graduate
P12	35-49	College Graduate
P13	65-74	College Graduate
P14	65-74	College Graduate

Table 2. NDPC Participant Demographic Data.

Participant	Age Group	Highest Degree Completed
P1	50-64	Postgraduate
P2	35-49	College Graduate
P3	35-49	High School or Less
P4	35-49	Postgraduate
P5	35-49	Postgraduate
P6	18-34	College Graduate
P7	18-34	College Graduate
P8	18-34	Postgraduate
P9	18-34	College Graduate
P10	50-64	College Graduate
P11	50-64	Postgraduate
P12	35-49	Postgraduate
P13	18-34	College Graduate
P14	50-64	High School or Less

Participant	Age Group	Highest Degree Completed
P15	35-49	College Graduate
P16	18-34	College Graduate
P17	18-34	Postgraduate
P18	35-49	College Graduate
P19	35-49	College Graduate
P20	50-64	College Graduate

Discussion

Quantitative Analysis

The System Usability Scale (SUS) was used to evaluate the usability of the ASL Consent App. It is important to understand that the SUS can only determine if a system is usable or not usable. It cannot determine why the system is usable or not usable. This can only be discovered through open ended questions and qualitative analysis. The SUS consists of 10 questions that are answered using a Likert scale rating from 1 to 5. A rating of 1 means “strongly disagree” and a rating of 5 means “strongly agree”. The overall SUS score is calculated using the formula by Brooke (1995) and scores range from 0-100. According to Bangor et al. (2008), the average SUS score is 70.14 and systems that score below 70 “should be considered candidates for increased scrutiny and continued improvement”. SUS scores above 70 are considered “passable” and “truly superior” systems have scores above 90 (Bangor et al. 2008).

The average SUS score across participants recruited from the DSA was 71.96 (s = 16.67). The average SUS score across participants recruited from NDPC was 71.25 (s = 17.65). The average SUS score across all participants from both the DSA and NDPC was 71.54 (s = 17.02). Given that the ASL Consent App is in its first iteration of user testing, an average SUS score of 71.54 is a sufficient indicator that our prototype is worthy of further development. Since the development of the ASL Consent App will involve many iterative versions that will be continually tested, the SUS scores of each iteration can be used as one metric to evaluate the progression of the system (Bangor et al. 2008). A table of the SUS scores for the DSA participants and NDPC participants are provided in Figure 5 and Figure 6, respectively.

Table 3. DSA Participants' SUS Scores.

Participant	SUS Score
P1	67.5
P2	65
P3	97.5
P4	50
P5	47.5
P6	80
P7	90
P8	82.5
P9	60
P10	50
P11	62.5
P12	87.5
P13	90
P14	77.5

Table 4. NDPC Participants' SUS Scores.

Participant	SUS Score
P1	95
P2	75
P3	90
P4	100
P5	72.5

Participant	SUS Score
P6	42.5
P7	75
P8	65
P9	32.5
P10	57.5
P11	95
P12	70
P13	87.5
P14	70
P15	85
P16	70
P17	77.5
P18	55
P19	50
P20	60

A one-way ANOVA test was used to determine whether there was a significant difference between the average SUS scores of different age groups. The chart in Figure 7 provides a visualization of the average scores between age groups. The age groups were divided into the categories of 18-34, 35-49, 50-64, and 65-74. The one-way ANOVA test revealed a p-value of 0.616 which indicates that there is not a significant difference between the average SUS scores of each age group. A one-way ANOVA test was also used to determine whether there was a significant difference between the average SUS scores for different education levels. The sample was divided into three groups according to the highest level of education completed by each participant. These groups were categorized as "high school or less", "college graduate", and "postgraduate". The chart in Figure 8 provides a visualization of the average scores between education levels. The one-way ANOVA test revealed a p-value of 0.136 which indicates that there is not a significant difference between the average SUS scores across education levels. A t-test was conducted to determine whether there was a significant difference between the scores of participants recruited from the DSA and participants recruited from the NDPC conference. The chart in Figure 9 provides a visualization of the average scores between participants from DSA and participants from NDPC. The t-test resulted in a p-value of 0.908 which indicates that there is not a significant difference between the two groups.

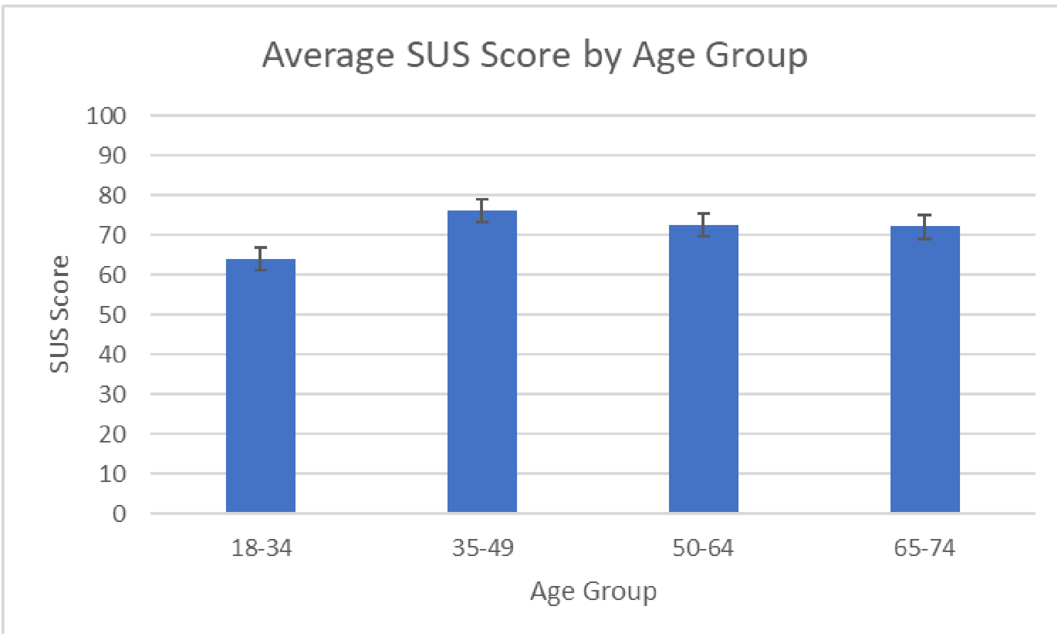

Fig. 3. Average SUS Score by Age Group.

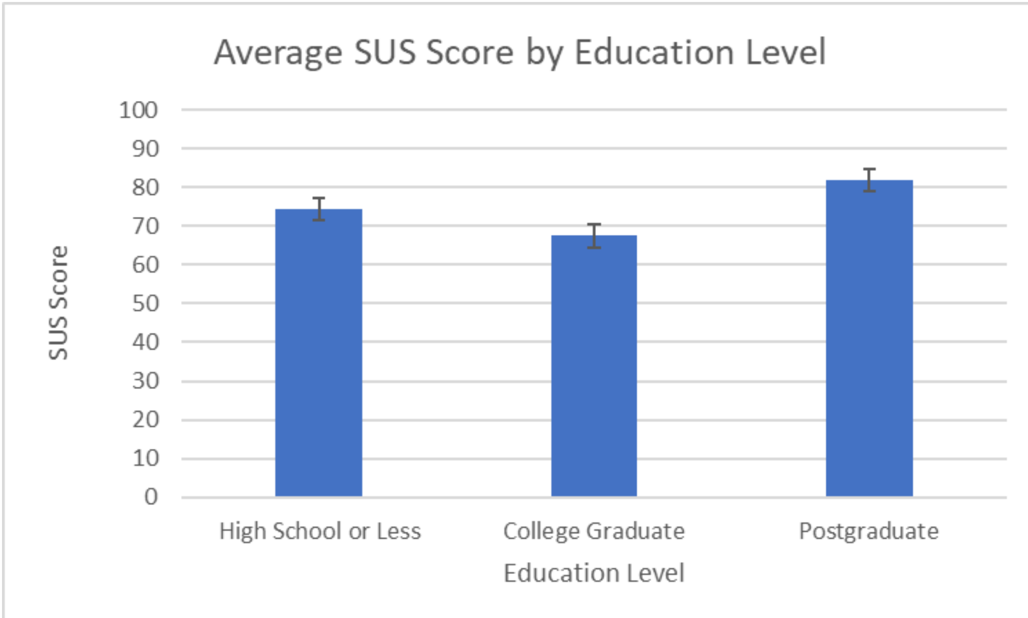

Fig. 4. Average SUS Score by Education Level.

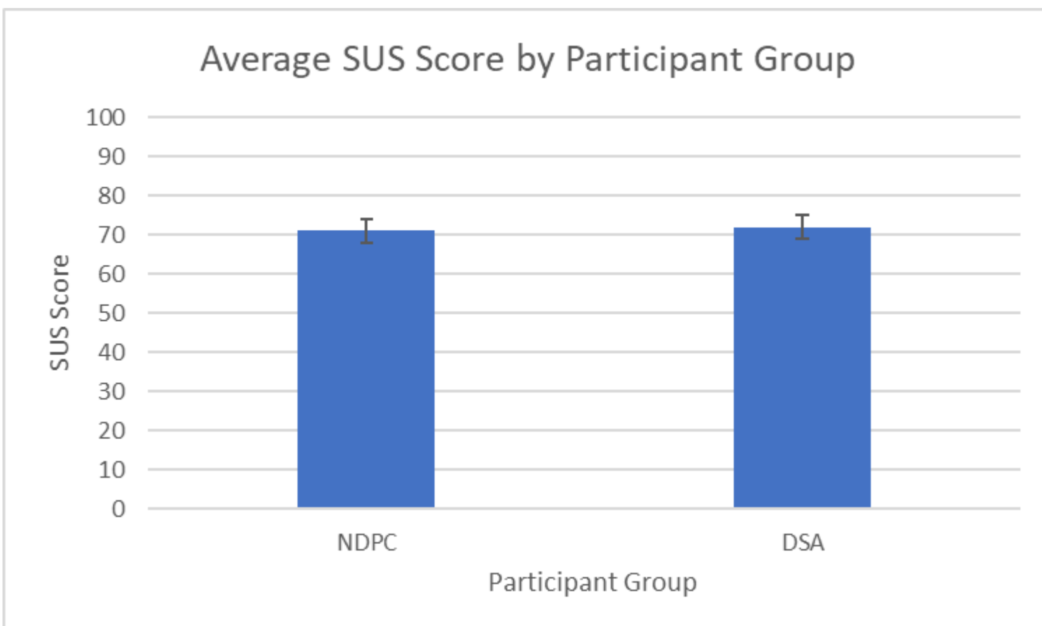

Fig. 5. Average SUS Score by Participant Group.

Qualitative Analysis (Thematic Analysis)

Participants from the NDPC conference were given the opportunity to provide feedback by typing their comments into a textbox or recording a video of themselves signing. Five participants utilized the textbox for feedback and participant feedback was generally positive. Four participants described the ASL Consent App as “easy to use”, “simple”, and “user-friendly”. One participant noted that “ASL instruction prior to use may help for those who are not tech savvy” which emphasizes the need for adequate user training. Developing a consistent system for user training may increase the overall usability of the ASL Consent App.

The participants at the DSA and NDPC conferences both commented that the positioning of the iPad camera made interacting with the application awkward because the body positioning was not intuitive. One NDPC participant said the camera being positioned on the side of the iPad when it was in landscape mode “made it a little bit awkward as I had to shift my body sideways to be centered in the viewfinder. If I didn’t do that and looked at myself, it looked like I was in the wrong position.”

The qualitative analysis of the open-ended feedback from participant video recordings at NDPC revealed four themes, seen in figure 9: the responsiveness, expansion, ease, and accessibility of the application. As predicted, the overall impression of the technology was positive and encouraged further development, with one user saying, “I am impressed that the app itself is very responsive, it is quick to catch whatever sign you throw at it.” 23% of respondents mentioned wanting to see this technology expanded and used in the real world. One participant mentioned how they could imagine this making other healthcare documentation, like living wills and Do Not Resuscitate paperwork, more accessible for DHH people who often do not understand these documents. The most common comment was on ease, with 50% of the feedback including this theme. Every participant who mentioned ease found the system clear, intuitive, and easy to use. One participant noted “because it’s smooth, easy… [and] interactive, yes, I quickly agree I would use this technology in the future.” Participants describing the system as easy to use indicates a likelihood to engage with this technology as a means to increase their access to healthcare information. 18% of participants commented explicitly on accessibility, all of them supporting the theme that this system will make documented healthcare information more accessible to DHH sign language users.

Table 5. Percentage of Themes Appearing in Participant Qualitative Feedback.

Theme	Percentage Present in Participant Responses
Responsiveness	23%
Expansion	23%
Ease	50%
Accessibility	18%

Conclusion

Our overall average SUS score of 71.5 indicates that our app development is moving in the right direction. The first round of participants were primarily senior citizens aged 65 years or older and this age group is generally less technologically literate than younger age groups. We followed the logic that if senior citizens were able to navigate the ASL consent app, then younger populations would likely be able to use our app easily. The participants recruited from the NDPC conference had a more diverse age range, with a majority of participants being under 50 years old. Overall, we were satisfied with the SUS feedback as a sign to continue this research.

Future Work and Limitations

There were a few limitations in the technology of our ASL consent app. One of the limitations is that the machine learning model used for sign language recognition was developed using healthy people as a model. Therefore, the app does not accommodate conditions which impact manual dexterity, such as arthritis. Some participants signed "Yes" using a handshape that had their thumb out rather than tucked in which would result in incorrect sign language recognition. In the future, the machine learning model needs to use more diverse datasets. Also, many participants used an ASL classifier for “Oh I see” (“OIC”) which could be considered as a sign to include in the machine learning model.

A prompting feature at the end of each video that asks users if they are ready to move to the next section would be helpful for users to understand when they should interact with the app. This feature would create a more conversational feel to the app. Additionally, the application could be modified to visually indicate when the camera is “looking” at the user, i.e., ready to receive prompts in ASL. This visual indication could take the form of animated eyes that open when the machine is receptive to ASL and closed when it is not.

As the application learns more language, this technology could be expanded and applied for industry interests beyond informed consent documents in research settings. This technology could theoretically be leveraged to provide sign language interactability for a variety of applications, making documents and apps accessible to sign language users in any context where paperwork is deployed.

Capturing sign language is necessary for creating datasets that can be used to train machine learning algorithms. These algorithms can then be used to recognize and translate sign language. The data collected from sign language capturing and translation can also be used to produce avatars or videos that use AI to generate a “human” animation that looks more realistic. These technologies can all be applied to fields such as healthcare, education, and general communication (Papastratis et al. 2021).

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Works Cited

Anderson, M. L., et al. (2020). Deaf ACCESS: Adapting consent through community engagement and state-of-the-art simulation. *Journal of Deaf Studies and Deaf Education*, *25*(1), 115–125.

Anderson, M. L., et al. (2018). Deaf qualitative health research: Leveraging technology to conduct linguistically and sociopolitically appropriate methods of inquiry. Qualitative Health Research, 28(11), 1813–1824.

Bangor, A., Kortum, P. T., & Miller, J. T. (2008). An empirical evaluation of the system usability scale. *International Journal of Human-Computer Interaction*, 24(6), 574–594. https://doi.org/10.1080/10447310802205776

Brooke, J. (1995). SUS - A quick and dirty usability scale. https://www.researchgate.net/publication/228593520

Bragg, Danielle, et al. Sign language recognition, generation, and translation: An interdisciplinary perspective. *Proceedings of the 21st International ACM SIGACCESS Conference on Computers and Accessibility*. 2019.

Desai, Aashaka, et al. ASL citizen: A community-sourced dataset for advancing isolated sign language recognition." arXiv preprint arXiv:2304.05934 (2023).

Gurbuz, S. Z., et al. (2020). A linguistic perspective on radar micro-doppler analysis of American Sign Language. *IEEE International Radar Conference (RADAR)*, Washington, DC, USA, 2020, pp. 232-237, doi:10.1109/RADAR42522.2020.9114818

James, T. G., et al (2022). They're not willing to accommodate deaf patients: Communication experiences of Deaf American Sign Language users in the emergency department. qualitative health research. *Qual Health Res*. 2022 *Jan;32(1)*:48-63. [doi: 10.1177/10497323211046238](https://doi.org/10.1177/10497323211046238)

Kosa, B. S., et al (2023). ASL consent in the digital informed consent process. *Journal on Technology and Persons with Disabilities*. CSUN Assistive Technology Conference. 288-305.

Kushalnagar P, Reesman J, Holcomb T, Ryan C. Prevalence of anxiety or depression diagnosis in Deaf adults. *J Deaf Stud Deaf Educ*. 2019 Oct 1;24(4):378-385. https://doi.org/10.1093/deafed/enz017

Kushalnagar, P. & Miller, C. (2019). Health disparities among mid-to-older Deaf LGBTQ adults compared to mid-to-older Deaf non-LGBTQ adults in the United States. *Health Equity*. https://doi.org/10.1089/heq.2019.0009

Kushalnagar, P., Paludneviciene, R., & Kushalnagar, R. (2019). Video remote interpreting technology in health care: Cross-sectional study of Deaf patients' experiences. *JMIR Rehabilitation and Assistive Technologies*, *6(1)*, e13233.

Kushalnagar, P., Harris, R., Paludneviciene, R., & Hoglind, T. (2017). Health information national trends survey in American Sign Language (HINTS-ASL): Protocol for the cultural adaptation and linguistic validation of a national survey. *JMIR Research Protocols*, *6*(9), e172.

McKee, M., Schlehofer, D., & Thew, D. (2013). Ethical issues in conducting research with deaf populations. *American Journal of Public Health, 103(12)*, 2174–2178.

McKee, M., et al. (2012). Engaging the Deaf American sign language community: lessons from a community-based participatory research center. *Progress in Community Health Partnerships: Research, Education, and Action, 6(3)*, 321–329.

National Institute on Minority Health and Health Disparities. Health disparities experienced among persons living with disabilities. *National Institute of Health*, 2022. https://www.nimhd.nih.gov/funding/approved-concepts/2022/health-disparities-among-persons-with-disabilities.html

National Science Foundation, National Center for Science and Engineering Statistics. Doctorate recipients from U.S. universities: 2017." *Special Report NSF* 19-301. 2017 https://ncses.nsf.gov/pubs/nsf19301/

Papastratis, I., Chatzikonstantinou, C., Konstantinidis, D., Dimitropoulos, K., & Daras, P. (2021). Artificial intelligence technologies for Sign Language. *Sensors*, 21(17). https://doi.org/10.3390/s21175843

Pérez-Stable, E., Otto Valdez, R. (2023). Announcement of Decision to Designate People with Disabilities as a Population with Health Disparities. *National Institute of Health*. https://nimhd.nih.gov/about/directors-corner/messages/health-disparities-population-designation.html

Sanfacon, K., et al (2020). Cross-sectional analysis of medical conditions in the U.S. deaf transgender community. *Transgender Health*. https://10.1089/trgh.2020.0028

Singleton, J. L., Jones, G., & Hanumantha, S. (2014). Toward ethical research practice with deaf participants. *Journal of Empirical Research on Human Research Ethics: JERHRE, 9(3)*, 59–66.

Willis, Athena, et al. Multimodal visual languages user interface, M3UI. *The Journal on Technology and Persons with Disabilities* (2019): 172.