ASL Consent in the Digital Informed Consent Process

Conference Paper · September 2023

CITATION
1

READS
107

6 authors, including:

Ai Minakawa
Gallaudet University
5 PUBLICATIONS **1** CITATION
SEE PROFILE

Patrick Boudreault
Gallaudet University
16 PUBLICATIONS **781** CITATIONS
SEE PROFILE

Poorna Kushalnagar
Gallaudet University
96 PUBLICATIONS **2,147** CITATIONS
SEE PROFILE

Raja Kushalnagar
Gallaudet University
43 PUBLICATIONS **367** CITATIONS
SEE PROFILE

2023
THE JOURNAL ON TECHNOLOGY AND PERSONS WITH DISABILITIES

ASL Consent in the Digital Informed Consent Process

Ben S. Kosa[1], Ai Minakawa[2], Patrick Boudreault[2], Christian Vogler[2], Poorna Kushalnagar[2], Raja Kushalnagar[2]
University of Washington[1]
Gallaudet University[2]
ben.kosa@gallaudet.edu, ai.takayama@gallaudet.edu, patrick.boudreault@gallaudet.edu, christian.vogler@gallaudet.edu, poorna.kushalnagar@gallaudet.edu, raja.kushalnagar@gallaudet.edu

Abstract

There is an estimated 500,000 people in the U.S. who are deaf and who use ASL and live in the U.S. Compared to the general population, deaf people are at greater risk of having chronic health problems and experience significant health disparities and inequities (Sanfacon, Leffers, Miller, Stabbe, DeWindt, Wagner, & Kushalnagar, 2020; Kushalnagar, Reesman, Holcomb, & Ryan, 2019; Kushalnagar & Miller, 2019). Much of the disparities are explained by the barriers in the environment, such as the unavailability of materials in ASL and lack of healthcare professionals who know how to provide deaf patient-centered care. Intersecting social determinants of health (e.g., intrinsic - low education; and extrinsic - barrier to healthcare services) create a mutually constituted vulnerability for health disparities when a person is deaf (Kushalnagar & Miller, 2019; Lesch, Brucher, Chapple, R., & Chapple, K., 2019; Smith & Chin, 2012). Moreover, the longstanding history of inequitable access to language and education, and a lack of printed information and materials, leave people who are deaf and use ASL unaware of opportunities to participate in cutting-edge research/clinical trials. An unintended consequence, therefore, is that PIs neglect to include people who are deaf and use ASL in their subject sample pools, and this marginalized population continues to be at disparity for health outcomes and also clinical research participation. One barrier is the unavailability of informed consent materials that are accessible in ASL.

Continue….

2023
THE JOURNAL ON TECHNOLOGY AND PERSONS WITH DISABILITIES

ASL Consent in the Digital Informed Consent Process

Ben S. Kosa[1], Ai Minakawa[2], Patrick Boudreault[2], Christian Vogler[2], Poorna Kushalnagar[2], Raja Kushalnagar[2]
University of Washington[1]
Gallaudet University[2]
ben.kosa@gallaudet.edu, ai.takayama@gallaudet.edu, patrick.boudreault@gallaudet.edu, christian.vogler@gallaudet.edu, poorna.kushalnagar@gallaudet.edu, raja.kushalnagar@gallaudet.edu

Continued…

The current research study conducted by our team at the Center for Deaf Health Equity at Gallaudet University attempts to address the language barrier to the consent process through a careful reconsideration of its traditional English format and the development of an American Sign Language (ASL) informed consent app. This team successfully leveraged existing machine learning methods to develop a way to *navigate* and *signature* an informed consent process using ASL. We call this new method of navigation and signature "*ASL consent.*" In our findings, we found that deaf people who are primarily college educated were more likely to agree that the process for obtaining *ASL consent* through an accessible app is comparable to traditional English consent.

Keywords

Deaf and hard of hearing, American Sign Language, Consent, Machine Learning.

Introduction

There is an estimated 500,000 people in the U.S. who are deaf and who use ASL and live in the U.S. Compared to the general population, deaf people are at greater risk of having chronic health problems and experience significant health disparities and inequities (Sanfacon, Leffers, Miller, Stabbe, DeWindt, Wagner, & Kushalnagar, 2020; Kushalnagar, Reesman, Holcomb, & Ryan, 2019; Kushalnagar & Miller, 2019). Much of the disparities are explained by the barriers in the environment, such as the unavailability of materials in ASL and lack of healthcare professionals who know how to provide deaf patient-centered care. Several researchers have conducted focus group discussions with deaf people who use ASL and identified many barriers and facilitators involved in the informed consent process (Singleton, Jones, & Hanumantha, 2014; Anderson et al., 2020). They also articulate a stated need to train researchers and interpreters on the topic of cultural competence when working with deaf people in research. As a result, two informed consent and research participation training products resulted from this earlier research; one ASL video targets deaf people who wish to learn more about informed consent, the other video targets hearing researchers who have little experience or working knowledge of deaf people who use ASL.

Reconsidering Traditional Informed Consent Procedures

The informed consent process ensures that participants understand the information and risks necessary to decide whether they want to participate in the research. However, in almost all research, the informed consent process is done entirely in written or spoken English with a reading level of high school or above. Often, deaf people's first natural language is ASL and they only learn written English as a second language later in life; this means that English literacy varies widely among deaf people who use ASL. This means most informed consent processes are

shown with a reading level higher than most deaf AND hearing participants can understand, as research also suggests an eighth-grade average reading level amongst high-school graduates in the U.S. (Easterbrooks, 2012).

Informed consent forms are also widely inaccessible due to their high use of health-related jargon, as a large majority of deaf sign language users have low-health literacy due to limited language access during key developmental periods and "a lifetime of limited access to information that is often considered common knowledge among hearing persons" (Anderson et al, 2020; McEwen & Anton-Culver, 1988, Kushalnagar 2017). Most informed consent protocols, which often include written English informed consent forms with complex jargon and legal terminology, fail to fully inform a deaf research participant and call for adaptations above-and-beyond simple translation of informed consent materials into ASL (Kushalnagar, 2018, Kushalnagar 2020).

To address this, the Center for Deaf Health Equity team at Gallaudet University received funding from the National Institutes of Health to develop a user-centered and low-resource informed consent toolkit that allows developers and researchers to easily create informed consent applications that are accessible to deaf people who use ASL. In order to develop this toolkit, two things need to first be proven: the informed consent process is more accessible when its **(1)** *content* is shown in ASL and **(2)** when it's *navigable* and *signaturable* in ASL.

As such, this paper aims to answer the following question: If the informed consent process in a research survey app instead allowed participants to navigate and consent in ASL, do deaf people who use ASLview this as equitable to the traditional informed consent process in-terms of **(1)** comprehension of what they are consenting to and **(2)** user friction in the consent process? This paper attempts to answer this question.

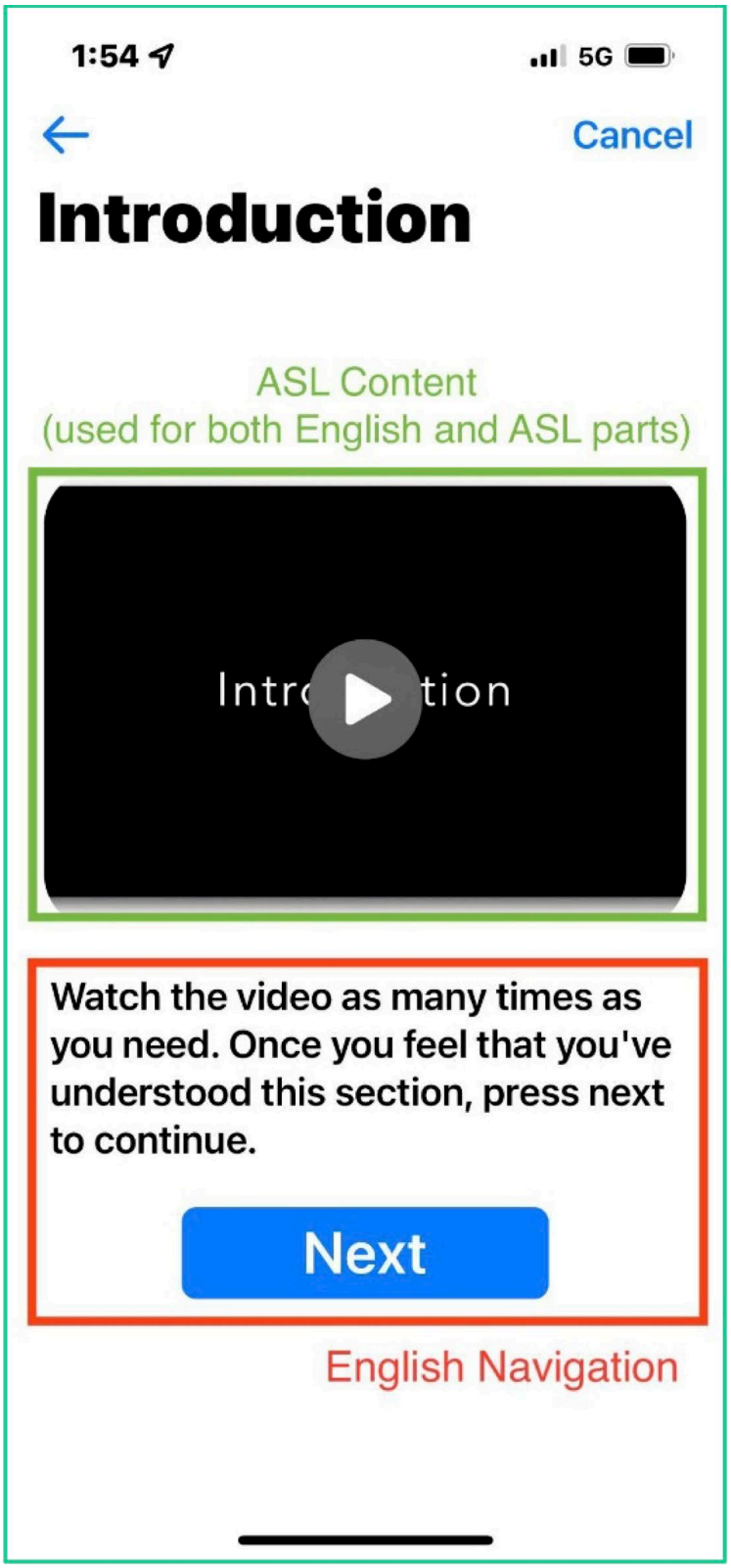

Fig. 1. A labeled English section in the ASL-Consent app with ASL Signature.

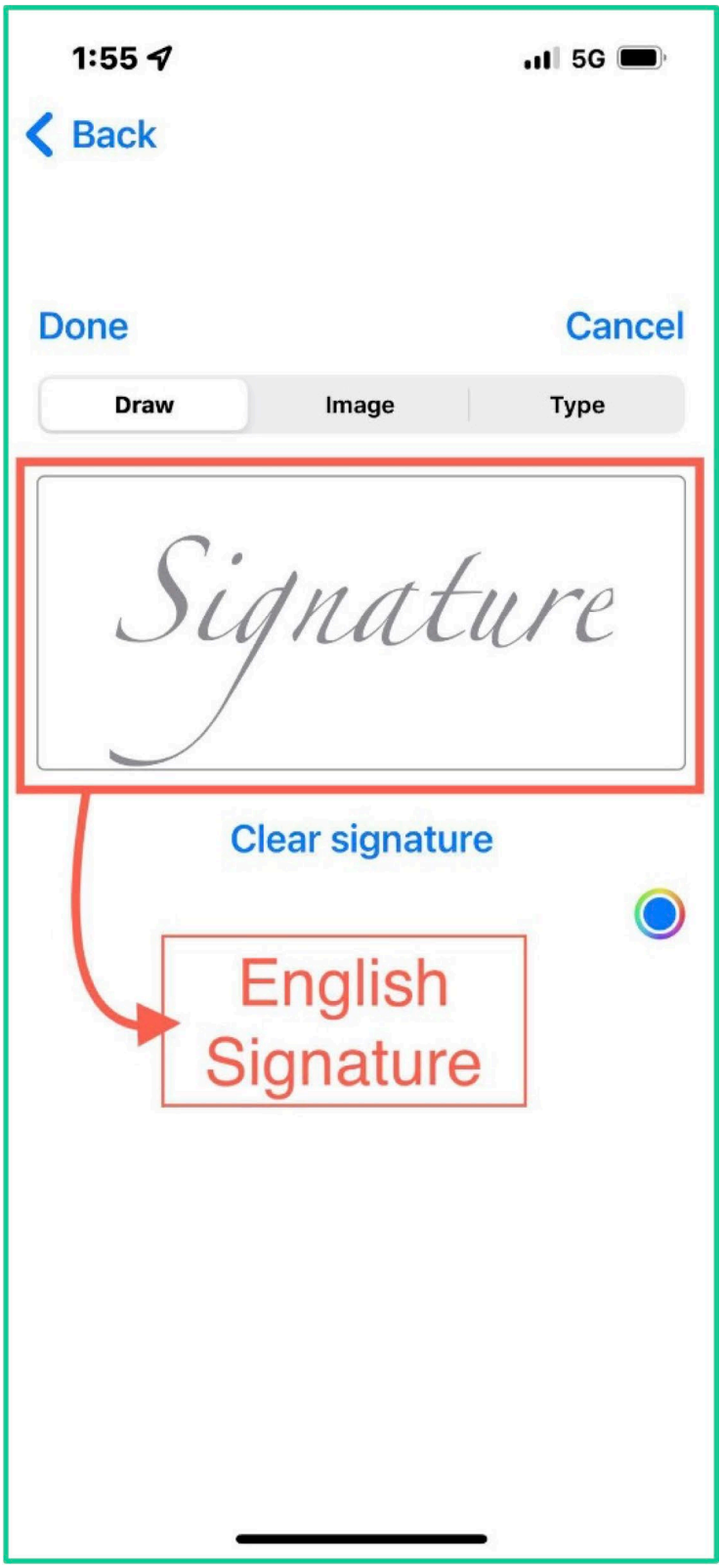

Fig. 2. A labeled signature section in the ASL-Consent app with English signature.

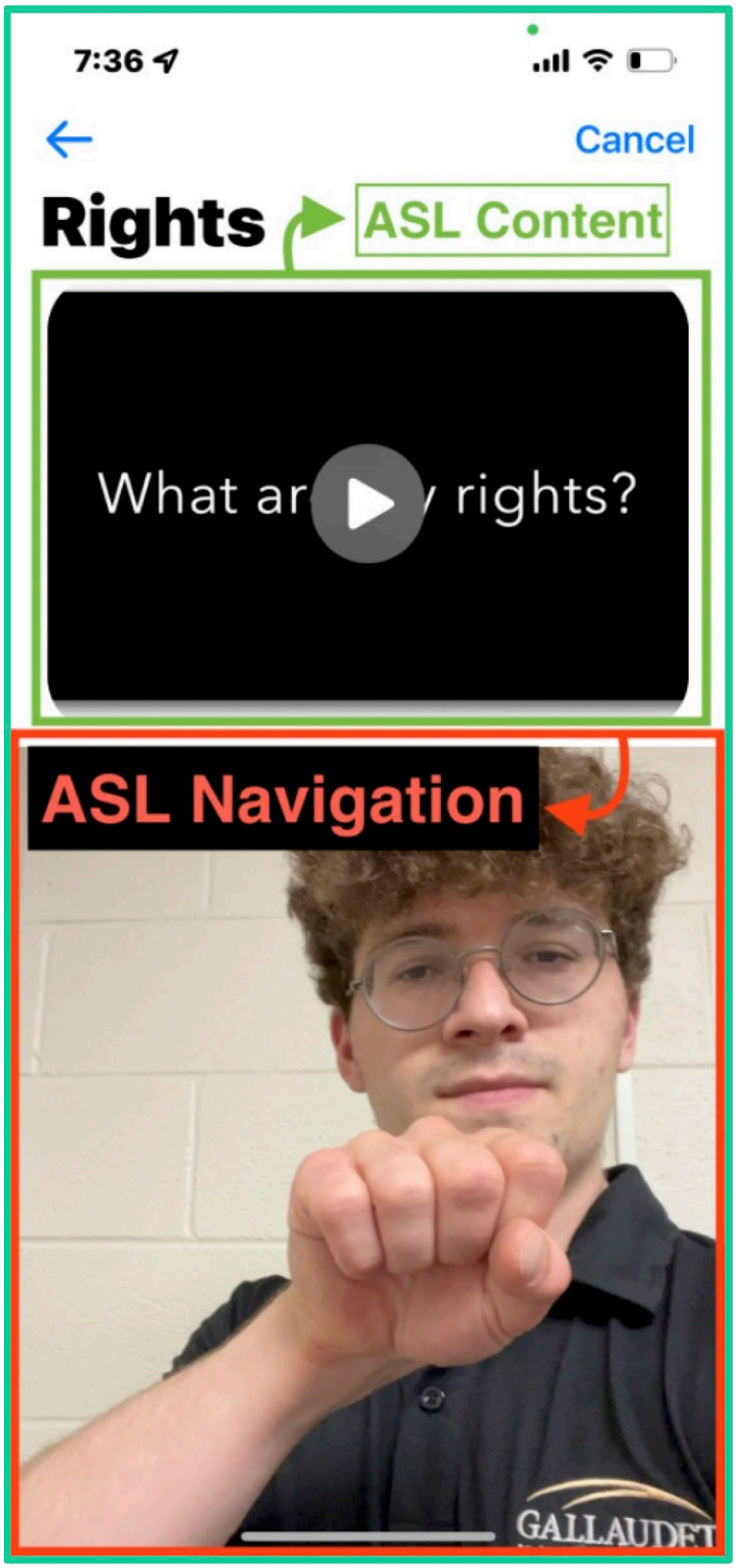

Fig. 3. A labeled ASL section in the ASL-Consent app with ASL content and ASL navigation.

Fig. 4. A labeled signature section in the ASL-Consent app with *ASL content* and *ASL navigation.*

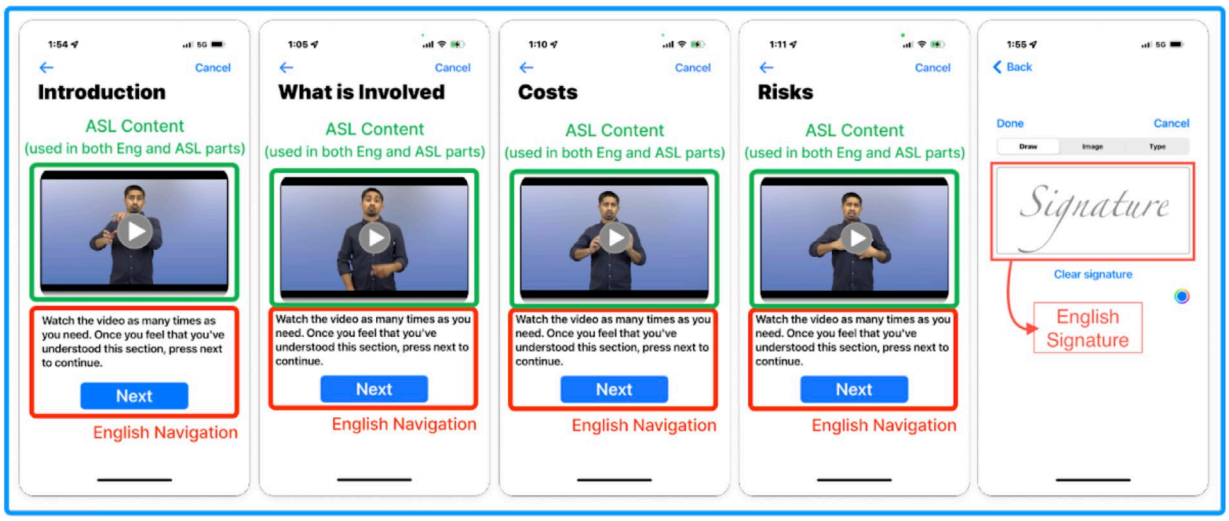

Fig. 5. The English Version of the ASL-Consent app.

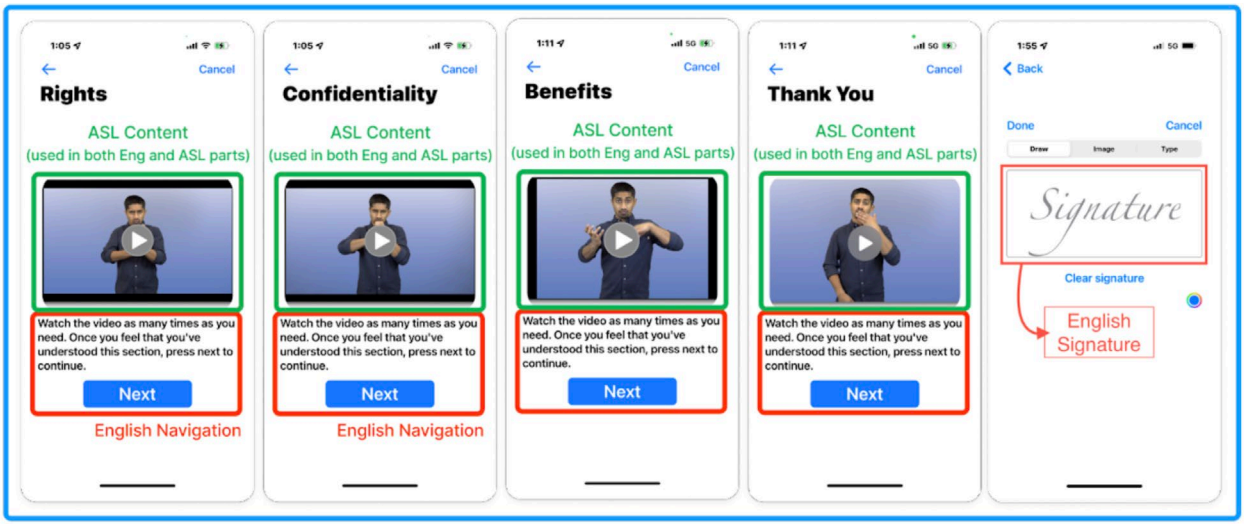

Fig. 6. The ASL Version of the ASL-Consent app.

Discussion

Methodology

To test whether making the digital informed consent process interactable in ASL would improve its accessibility for deaf participants, we developed an iOS mobile app that presented two different versions of the informed consent process to compare two conditions: *English* vs. *ASL navigation* and *English* vs. *ASL signature*. Both informed consent processes were made up

of 8 sections of ASL content videos and a signature page, but the *English Version* (Fig. 5) required the participant to navigate from one section to the next through a traditional "English button" and provide a traditionally English "pen-and-paper" signature. The *ASL Version* (Fig. 6) on the other hand, required the participant to navigate from one section to the next by signing "yes' in front of their camera and providing their signature by fingerspelling their full name in ASL. The *ASL Version* also had instructional videos that would play after each ASL content video and explain in ASL how to navigate to the next section using "ASL navigation" and sign the digital consent form with fingerspelling.

With the app, we performed a user experience study with 15 deaf participants who were at least 18 years or older and whose primary language was American Sign Language. With each participant, we tested the two conditions through a one-hour A/B testing session over Zoom where one half of participants were shown the English version first and ASL version second and the other half of participants were shown the ASL version first and English version second.

After showing both the English and ASL versions, participants were asked to respond to nine different standardized usability questions through a 5-point Likert scale. After answering these questions, participants were asked to share any feedback they had about the English and ASL versions or feedback they had about the app in general. For their time, each participant was compensated $25.

Results

Demographics

Ten of the participants self-identified as female, 5 self-identified as male, and 1 self-identified as non-binary. Age ranged from 33 to 77 years of age (mean age = 36 years; SD = 1.41). 10 participants self-identified as White; 3 self-identified as Asian; and 3 self-identified as

Black. Most of our participants were college educated (13% with some college; 63% with a college degree; 25% with a postgraduate degree). As for the geographical distribution of our participants across the United States, 13% of participants were from the East, 19% were from the Midwest, 13% were from the Northeast, 25% were from the South, 6% were from the Southwest, and 25% were from the West.

Quantitative Results

Fig. 7 summarizes the responses participants gave by showing the mean average response for each of the nine user experience questions. To compare the difference in how users felt about the *English part* and *ASL part*, we performed a T-Test on each question to see if there was significant difference. For each question's T-Test, it compared the means between the responses for the "English-system" and the "ASL-system." *Table 1* includes each question and summaries the results for each of their T-Tests.

Table 1. Quantitative responses from our 9 user experience questions regarding participant perceived experience navigating and signaturing in the *English* and *ASL parts.*

* Each question was asked in two separate parts (a) and (b) for the English part and ASL part and the participant gave an answer for both parts separately.

Evaluation Question*	**Summary of Responses**
1. I found the (a) English-system (b) ASL-system unnecessarily complex.	Most people said both the English section and ASL Sections were not complicated or had little-to-no complication.
2. (a) I feel comfortable using the (a) English (b) ASL system.	Most participants felt that both English and ASL navigation and signature were "easy-to-use".
3. I thought the (a) English-system (b) ASL-system was easy to use.	Most participants felt that both English and ASL navigation and signature were "easy-to-use".
4. It was easy to learn to use the (a) English-system (b) ASL-system.	Most participants said that both versions felt "fairly easy" or "easy" to learn.

Evaluation Question*	Summary of Responses
5. Using the (a) English-system (b) ASL-system was a frustrating experience.	Most participants said that both versions were "barely frustrating" or "not frustrating at all."
6. It was easy to provide my signature at the end of the (a) English-system (b) ASL-system.	Most participants said that both versions were easily signaturable.
7. Overall, I am NOT satisfied with the amount of time it took to navigate to the next section in the (a) English-section (b) ASL-section.	Most participants said that they felt that English and ASL navigation ranged from feeling like a "medium length of time" to "fairly short" or "very short."
8. Overall, I am NOT satisfied with the amount of time it took to provide my signature at the end of the (a) English-system (b) ASL-system.	Most participants said that they felt both the English and ASL signature was "fairly short" or "very short."
9. The (a) English-system (b) ASL-system has all the function and capabilities I expect it to have	Overall, participants felt the ASL navigation and signature met their needs and expectations more than the English navigation and signature.

No Significant Difference

After calculating all the p-values for each question one through 9, none of which had significant difference, we found there is no significant difference in the user experience between the *English part* and *ASL part*.

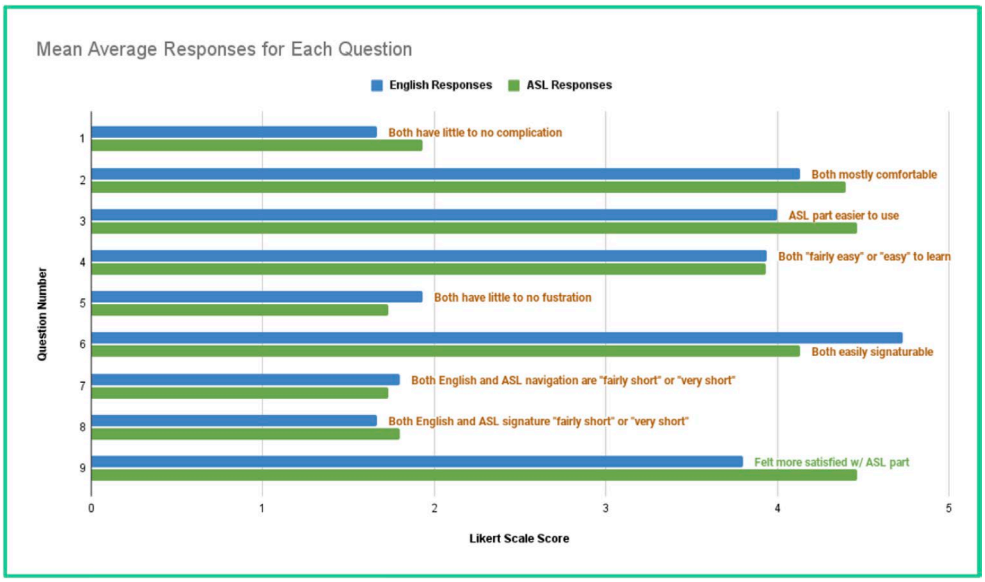

Fig. 7. The mean average of the responses for each of the 9 quantitative questions.

Qualitative Feedback

Overall, participants felt that *ASL navigation* and *signature* felt overall equivalent to or better than their English counterparts. Most participants also openly expressed that they were excited about the general concept of *ASL navigation* and *signature* and felt it was "worth it for deaf people who use ASL."

For the ASL signature section however, participants noted that spelling your full name in ASL felt tedious, especially for those with long names, and felt signing their initials or "I consent" would be faster. One of the biggest concerns amongst participants was that ASL navigation and signature are totally new concepts and will present a learning curve regardless of how much deaf signers like them in the long run. ASL navigation and signature will need to be implemented with this in mind, making good use of an instructional or onboarding process. In line with satisfying the entire community that self-identifies as deaf, deafblind, or hard of hearing, which has a wide diversity of language backgrounds, many participants also suggested giving users the option to pick between traditional English and ASL navigation and signature as well as the option to pick different singing styles for the ASL instructional videos (i.e., Black ASL, West Coast ASL, East Coast ASL, slower signing, faster signing, etc.).

Conclusion

The quantitative responses and qualitative responses show that the deaf participants are in agreement that *ASL navigation* and *signature* in an informed consent app are at least equal to the traditional *English navigation* and *signature* that they are used to. However, we noticed that participants really liked the concept of *ASL navigation* and *signature* but didn't like the way that we implemented it as much. Participants felt that having the ASL content videos only watchable in a full screen mode that took you out of the ASL section screen interrupted the flow of the *ASL*

navigation, as it forced the user to have to hit "x" in the top left corner to go back to the section screen before they could respond with "yes." Participants also felt this flow was interrupted by having the same ASL instructions play at the end of each section. Instead of having the ASL instructional videos appear right after each ASL content video, one participant recommended showing it only once before the user starts the informed consent process. If the user ever needed to reference the instructions, they could click on a small button in the corner of the screen to view that section.

The *ASL signature* section also suffered from a similar issue. The ASL instructions for the section need to be improved, along with how the process itself is done. Many participants felt that spelling out their entire name was too tedious and recommended it would be better to let the user fingerspell only their initials or "I consent."

Regardless, it was clear that participants really liked being able to sign "yes" and being able to automatically move to the next section.

Limitations

As with any piece of research, this study had many limitations. The sample used for this study was very small (only 15 people) and wasn't very diverse. Most participants had at least obtained a college degree (88%) and thus represented only 18% of deaf people in the U.S (Garberoglio, Cawthon, & Sales, 2019). This is even more significant when considering a deaf individual who grew up using bilingual ASL and English tends to be much more comfortable and fluent in English than an individual who grew up using primarily ASL with less access to English.

There were also many limitations to having the app evaluation interviews over Zoom. As we couldn't put the ASL-Consent app onto the app store for participants to download and install

on their own devices, they couldn't test the app for themselves. So, all their responses and feedback have been based on the user experience they had to assume they would have had if they had tested the app themselves. There were also times where technical bugs would plague our interview sessions and force our principal interviewer to stop and restart the app in the middle of the live demonstration. Zoom itself had some limitations as well, as there were times when the participant's screen wasn't big enough to see everything that was being demonstrated.

Future Work

Using the feedback collected from this study, we hope to further develop and improve the ASL-Consent app for a second study with a larger, more diverse group of deaf participants. It is especially important that the group is diverse in its language and education backgrounds, with emphasis on deaf people who use English as a second language. This subgroup is more likely to be marginalized from research participation that requires ability to read and provide consent in English. This second study would also need to be done in a way where the participant can test the ASL-Consent app for themselves. This means app evaluation interviews would either need to be done in-person with the app downloaded and installed on the principal interviewer's phone, or over Zoom with the app downloadable from the app store.

To address feedback from participants, the app used for the second study will replace the ASL instructional videos with a short onboarding process that will take place before the participant starts the informed consent process. The app will also include an updated UI that helps ASL navigation and signature flow better, a simpler way to provide your signature in ASL, and accessibility for participants who self-identify as deaf-blind or low vision.

After the completion of this study, and after the benefits of an app-based informed consent process with fully-ASL *content* and *consent* have been validated, we hope to develop an

app-based, accessible informed consent toolkit that researchers nationwide can use to make their app-based studies more accessible to deaf people who use ASL. We won't be making this toolkit from scratch however, as many researchers already make use of Apple's ResearchKit framework. ResearchKit is an open-source framework that allows researchers to easily make powerful iOS apps for medical research with visual consent flows, real-time dynamic active tasks, and surveys.

For future development of *ASL content* in an informed consent app, feedback from participants strongly suggests that a hybrid approach, or an approach that provides both options: purely English and purely ASL, is the best option to meet the needs of deaf people who use ASL.

Acknowledgments

This work was supported by NSF REU Site Grants (#1757836 and #2150429) awarded to Dr. Raja Kushalnagar, PI and Dr. Christian Vogler, Co-PI. This work was also supported by the National Library of Medicine (NLM) of the National Institutes of Health (G08LM013797 awarded to Dr. Poorna Kushalnagar).

Works Cited

Anderson ML, Riker T, Hakulin S, Meehan J, Gagne K, Higgins T, Stout E, Pici-D'Ottavio E, Cappetta K, Wolf Craig KS. "Deaf ACCESS: Adapting Consent Through Community Engagement and State-of-the-Art Simulation." *J Deaf Stud Deaf Educ,* vol. 25, no. 1, Jan 2020, pp. 115-125, https://doi.org/10.1093/deafed/enz035

Bailey, Nicole, et al. "Evaluation of an American Sign Language co-curricular training for pharmacy students," *Currents in Pharmacy Teaching and Learning*, vo. 13, no. 1, 2021, pp. 68-72, https://doi.org/10.1016/j.cptl.2020.08.002

Berke, Larwan, et al. "Design and Psychometric Evaluation of American Sign Language Translations of Usability Questionnaires." *ACM Transactions on Accessible Computing*, vol. 12, no. 2, June 2019, pp. 1-43, doi: https://doi.org/10.1145/3314205

Boudreault, Patrick, et al. "Multimodal Visual Languages User Interface, M3UI." *Journal on Technology and Persons with Disabilities,* vol. 7, 2011, pp. 172-182, http://hdl.handle.net/10211.3/210399

Brooke, John. "SUS: A quick and dirty usability scale." *Usability Evaluation in Industry*, no. 194, 1996, pp. 189-194

Easterbrooks, S. R., & Beal-Alvarez, J. S. (2012). States' Reading Outcomes of Students Who Are d/Deaf and Hard of Hearing. American Annals of the Deaf, 157(1), 27–40. http://www.jstor.org/stable/26235186

Finstad, Kraig. "The usability metric for user experience." *Interacting with Computers*, vol. 22, no. 5, Sept 2010, pp. 323-327, https://doi.org/10.1016/j.intcom.2010.04.004

Garberoglio, CL, Palmer, J., Cawthon, S. & Sales, A. (2019). "Deaf People and Educational Attainment in the United States: 2017." *Washington, DC: U.S. Department of Education, Office of Special Education Programs, National Deaf Center on Postsecondary Outcomes.* http://dx.doi.org/10.26153/tsw/10052

James R. Lewis. "IBM computer usability satisfaction questionnaires: Psychometric evaluation and instructions for use." *International Journal of Human–Computer Interaction*, vol. 7, no. 1, 1995, pp. 57-78, https://doi.org/10.1080/10447319509526110

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. "Health Information National Trends Survey in American Sign Language (HINTS-ASL): Protocol for the Cultural Adaptation and Linguistic Validation of a National Survey." *JMIR Res Protoc.,* vol. 6, no. 9, Sep 2017 pp. 172. https://doi.org/10.2196/resprot.8067. PMID: 28903891; PMCID: PMC5617902.

Kushalnagar, P et al. "Deaf patient-provider communication and lung cancer screening: Health Information National Trends survey in American Sign Language (HINTS-ASL)." *Patient education and counseling* vol. 101,7 (2018): 1232-1239. https://doi.org/10.1016/j.pec.2018.03.003

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

Lesch H, Burcher K, Wharton T, Chapple R, Chapple K. Barriers to healthcare services and supports for signing deaf older adults. Rehabil Psychol. 2019 May;64(2):237-244. https://doi.org/10.1037/rep0000252

McEwen E, Anton-Culver H. The medical communication of deaf patients. J Fam Pract. 1988 Mar;26(3):289-91. PMID: 3346631.

Sanfacon, K., Leffers, A., Miller, C., Oliver, S., DeWindt, L., Wagner, K., & Kushalnagar, P. (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. https://doi.org/10.1177/1556264614540589

Smith, S.R., & Chin, N.P. (2012). Social Determinants of Health in Deaf Communities. https://doi.org/10.5772/38036