# Ideating for Co-designing with Blind and Visually Impaired Users:

## Exploring Possibilities for Designing User-Centered Healthcare Information in Pandemic Conditions

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**Abstract.** Access to information about the pandemic has been a major invisible barrier for people with visual impairments. As governments around the globe rush to distribute guidelines for the prevention of COVID-19 infections, the websites neglected to follow accessibility standards; thus, leaving out millions of users. Similar problems have been reported in acquiring information about medical help, such as locations for getting tested for COVID and even information about hospitals that accepted infected patients. On the other hand, digital-economy based rideshare services in many cases refused blind passengers, particularly if their destination was a medical facility. This problem has particularly been aggravated due to the absence of an easy-to-use, accessible reporting mechanism for the denial of such services by individual drivers. Those of us who have worked side by side with blind colleagues as participants in our design work, or as co-designers, are not unfamiliar with expressions of serious concern about the availability of information and reliability of technological infrastructure. Life for a majority of blind people, users, designers, academics, and citizens, was always unpredictable and it is definitely so in these pandemic times. This late-breaking poster paper presents the preliminary results of an in-progress survey of blind and low vision users in the United States which gauges the accessibility of healthcare information and related services during this pandemic. The results thus far reveal major identifiable access barriers to healthcare information on websites, HCI issues with telemedicine, information and reservation process about accessing COVID-19 vaccine sites, and digitally-dependent transportation.

**Keywords:** Accessibility to healthcare information for blind · Telehealth · Healthcare survey

## 1 Introduction

While the current pandemic offers some hope as medical providers have employed the tools of telemedicine so that medical professionals could make virtual visits with their patients using teleconferencing systems, not all patients have this access [1–3]. Likewise, medical economy supported by digital devices has also bestowed some autonomy on

C. Stephanidis et al. (Eds.): HCII 2021, CCIS 1499, pp. 47–55, 2021.
https://doi.org/10.1007/978-3-030-90179-0_7

patients for conducting basic medical tests to protect them from unnecessary exposure to infections in hospitals and clinics in these times of physical isolation and social distancing but again these affordances of technology did not reach a portion of disabled users. These pandemic concerns have been documented in public health literature in recent decades [4–6]. Those of us who have worked side by side with disabled colleagues as participants in our design work, or as co-designers, are not unfamiliar with expressions of serious concern about the availability of information and reliability of technological infrastructure because life for a majority of disabled people, users, designers, academics, and citizens, was always unpredictable but it is definitely so in these pandemic times [7]. Due to the ubiquitous presence of digital media in the operation of all these services and the embedding of digital interfaces in their delivery to patients, interaction designers with diverse expertise can play a central role in conceptualizing a more robust healthcare information infrastructure that does not fail disabled users.

## 2 Healthcare Information Access Issues for Blind and Visually Impaired Population During COVID-19

Accessibility has been defined as “all people, particularly disabled and older people, can use websites in a range of contexts of use, including mainstream and assistive technologies; to achieve this, websites need to be designed and developed to support usability across these contexts” [8]. A more comprehensive definition of accessibility comes from the perspective of web design which claims that “the ability to use, enjoy, perform, work on, avail of, and participate in a resource, technology, activity, opportunity, or product at an equal or comparable level with others. Separate is not equal and before or after the fact is also not equal” [9].

Access to information about the pandemic has been a major invisible barrier for people with visual impairments. As governments around the globe rush to distribute guidelines for the prevention of COVID-19 infections, the websites neglected to follow accessibility standards; thus, leaving out millions of users [10, 11]. Similar problems have been faced in acquiring information about medical help, such as locations for getting tested for COVID and even information about hospitals accepted infected patients.

On the other hand, many digital economy-based rideshare drivers refused disabled passengers, particularly if their destination is a medical facility. These transportation barriers themselves denied access to medical help because many disabled people do not drive and may not have a relative to give them a ride. This problem has particularly been aggravated due to the absence of an accessible reporting mechanism for the denial of such services by individual drivers. More carefully conceptualized digital interfaces and human computer interactions would have prevented such discriminatory actions on behalf of gig services that are otherwise considered a major achievement of the digital economy. Also, the transportation services support integrated in the EPIC System’s MyChart for patients requiring help in reserving rides is not available to patients seeking medical assistance for suspected COVID infection.

Digital interfaces also have great potential for tackling with the accessibility barriers faced by disabled patients within the medical facilities. Social distancing and masking guidelines particularly restrict blind and deaf patients in communicating with medical professionals and few hospitals and clinics adopted existing digital technologies to accommodate the needs of these groups. Even during the virtual appointments, the medical providers have little understanding of how they could adopt their digital interfaces to meet the needs of blind and deaf patients.

While a pandemic like COVID-19 is a natural phenomenon beyond human control, public health policies, human ethics, and professional and social prejudices play a crucial role in how the relief efforts are targeted at certain population and ignore others. Disabled populations in such dire situations are often forgotten in logistical preparedness and as the society mobilizes its healthcare and other resources, the disabled are again overlooked in the frenzy of the moment [4]. This inequity became painfully obvious in March 2020 when countries imposed lengthy lockdowns on its populations and permitted limited movement of essential workers, or people travelling in private vehicles. More importantly, the general information about COVID-19, communications about the access to testing facilities, availability of hospital beds for infected people, and later vaccination related resources excluded the disabled and the elderly. Only users of up-to-date technology, such as, smartphones and other hand-held devices could acquire this information. State and private sector websites often expected speedy interactions with websites to make appointments for vaccine. Many department of health websites were not accessible to screen reader users [12].

In this late breaking paper, we present the preliminary results of a national survey with blind and low-vision users on the accessibility of healthcare information.

## 3 Brief Literature Review

Accessibility of healthcare information to blind and low vision people has not been studied extensively in the past; however, abundant research has taken place on the accessibility of websites, smartphone applications, health devices, telehealth, electronic health records, and digitally-dependent transportation [13–15]. Some of this research has primarily focused on the accessibility of technologies to blind or low vision people, or to the broader category of disabled people [10].

People with disabilities, including blind and low vision people, have lesser access to healthcare information on the Web, compared to people without disabilities [16, 17]. Healthcare information on the Web is not exempt from this issue. In fact, a study evaluating the accessibility of 697 Portuguese and Spanish healthcare institutions' websites found that none of them were WCAG 2.0 compliant [18]. In the same study, a specific analysis of 40 websites chosen from the larger list found that even the most accessible websites had several inaccessible elements. Meanwhile, others had hundreds of inaccessible elements. More specifically, a study on COVID-19 information found that blind and low vision users had lower exposure to graphical data on COVID-19 [10]. Automatically updating graphics and interactive graphics were reported to often lack alt text or descriptions, and even sources with some accessible graphics were inconsistent and unreliable. Similarly, in a study of COVID-19 information accessibility to blind users, data visualizations on the Web were found to be typically inaccessible [11]. This survey found that the majority of respondents reported inaccessible data-driven media, while the majority of respondents also rated access to data driven articles as very important or extremely important. Major issues reported were incompatibility with screen readers as well as missing alt text and tabular data. Respondents addressed these issues by looking for data in textual or auditory forms or relying on visual interpretation.

Healthcare information can also be accessed through smartphone apps by the blind; however, smartphone apps are often not fully accessible. One study found that usage speed was slower than sighted people even among expert, blind smartphone users [19]. Likewise, popular videoconferencing platforms, including Zoom, MS Teams, and Google Meet, have all been found inaccessible to varying levels [20]. Despite claiming compliance to standards, such as WCAG 2.1 AA, exceptions are noted in each platform, which indicates a lack of full accessibility [21].

## 4 Purpose and Design of This Study

This study avoids simply collecting reports from experts, or bystanders, and concentrates on identifiable access barriers to healthcare information and computer mediated interactions through a detailed survey with blind and low vision population in the United States. The second phase of the study will also include a set of focus groups with the survey participants available to speak to the researchers.

By the closing of this survey, we hope to involve up to 200 blind and low vision participants in this project—a significant number in the context of this population. The survey includes questions about the availability of relevant informational technology in the healthcare context, the barriers blind users experienced in using this technology, HCI issues experienced by adaptive and assistive technology users and the healthcare information infrastructure, and the technology gaps identified by these users.

## 5 Methods

This study employs a mixed method survey tool to collect data about accessibility barriers to healthcare information from blind and low vision users. The preliminary data from the participants is extensive which cannot be included in this poster paper. In the second phase of the study, we will employ an additional qualitative tool -several focus groups with select blind and low vision participants who might have volunteered to contribute.

## 6 Preliminary Quantitative Data

Based on the data collected thus far from the survey, this paper tries to portray the accessibility barriers experienced by blind and low vision users. These barriers range from difficulties in acquiring online information due to the accessibility problems with the state and federal government websites to inaccessible interaction design of online forms for making reservations for COVID-19 testing. The overall user experience with websites was patchy in general, even when participants were eventually able to obtain the healthcare information they needed about COVID-19. Although the users did not particularly complain about the accessibility of data visualization tools on the websites offering information about COVID-19 infection rates, they did not seem to have sufficient information about these rates. Similarly, the participants did not always point out the difficulties they faced with digital economy-based rideshare services; however, many disabled users of these services face accessibility barriers, even in non-COVID times, because Uber and Lyft drivers regularly refuse to take passengers with service animals on their vehicles. Later in the conclusion, we try to imagine how participatory interaction design approaches with the involvement of blind participants could produce ideas for creative and effective HCI solutions in healthcare information contexts. The preliminary qualitative data from our survey also suggests that the participants ideas from this survey could provide HCI community with some new avenues for conducting socially focused and inclusive research [22, 23]. The study's overall approach is to identify problems through participation of this population in this survey and focus groups to come up with ideas using participatory design-oriented ideation to overcome these access barriers. For example, researchers have proposed methodologies employing a knowledge engineering approach to data sharing to protect patient privacy while deriving necessary information from health records [24].

A total of n = 71 blind and low vision US residents responded to our survey at this preliminary stage of the study. All participants did not answer all questions; therefore, data may not always add up to these totals. Table 1 offers basic demographic data about the participants. In our final report on this survey, we will also have participant data on race and ethnicity.

**Table 1.** Demographic data from the survey.

| | Disability Status | | Gender | | | Age | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Blind | Low-vision | Male | Female | Other | 18–24 | 25–34 | 35–44 | 45–54 | 55–64 | 65–74 | 75–84 |
| Count | 52 | 19 | 18 | 52 | 1 | 7 | 11 | 12 | 11 | 14 | 15 | 1 |
| Percentage | 73.2 | 26.8 | 25.4 | 73.2 | 1.4 | 9.9 | 15.5 | 16.9 | 15.5 | 19.7 | 21.1 | 1.4 |

Table 2 presents survey results about the availability of information on COVID-19 prevention measures to the participants.

**Table 2.** Availability of preventative COVID-19 information.

| | Masks (low vision) | Social Distancing (low vision) | Handwashing (low vision) | Masks (blind) | Social Distancing (blind) | Handwashing (blind) |
|---|---|---|---|---|---|---|
| Yes (count) | 18 | 17 | 17 | 43 | 42 | 48 |
| Yes (percent) | 94.7 | 89.5 | 89.5 | 84.3 | 82.4 | 94.1 |
| No (count) | 1 | 2 | 2 | 8 | 9 | 3 |
| No (percent) | 5.3 | 10.5 | 10.5 | 15.7 | 17.6 | 5.9 |

Table 3 includes data on the availability of various medical services and information about them to blind and low vision people. All participants did not answer every question.

**Table 3.** Availability of essential healthcare from medical providers during COVID-19 pandemic.

| | Prescription for a medication | Telemedicine | Regular therapy | Rehabilitation for a recent injury/medical condition |
|---|---|---|---|---|
| Equal access (count) | 39 | 27 | 35 | 26 |
| Equal access (percent) | 56.5 | 39.1 | 50.7 | 37.7 |
| Somewhat equal access (count) | 22 | 21 | 10 | 6 |
| Somewhat equal access (percent) | 31.9 | 30.4 | 14.5 | 8.7 |
| No access (count) | 6 | 10 | 10 | 15 |
| No access (percent) | 8.7 | 14.5 | 14.5 | 21.7 |
| Not applicable (count) | 2 | 11 | 14 | 22 |
| Not applicable (percent) | 2.9 | 15.9 | 20.3 | 31.9 |

Table 4 offers findings about the availability of delivery services for prescription drugs to blind and low vision users. Many respondents did not answer all the questions in this section.

**Table 4.** Availability of pharmacy delivery services to blind and low vision patients.

| | Free prescriptions delivery | Paid prescriptions delivery | Free prescriptions by mail | Paid prescriptions by mail | Family picking up prescriptions | Volunteer picking up prescriptions | Participant picked up prescriptions |
|---|---|---|---|---|---|---|---|
| Yes (count) | 26 | 15 | 27 | 15 | 46 | 18 | 35 |
| Yes (percent) | 37.7 | 21.7 | 39.1 | 21.7 | 66.7 | 26.1 | 50.7 |
| No (count) | 43 | 54 | 42 | 54 | 23 | 51 | 34 |
| No (percent) | 62.3 | 78.3 | 60.9 | 78.3 | 33.3 | 73.9 | 49.3 |

## 7 A Sampling of Qualitative Data

In the section below we share a summary of select qualitative responses due to space limitations. In our qualitative data, participants' responses varied not only by their blindness or low vision status, but also by the specific accessibility barriers they faced. In our discussion of these results, we maintain most of the differences that participants stated in their accessibility problems, unless the categories were either collapsible or were subcategories of a category, such as graphics and graphs.

Three (4.2%) participants also reported compounded accessibility issues due to their multiple disabilities.

When we asked if participants experienced equal healthcare information access as blind or low-vision consumers, 25 (48.1%) blind and 13 (68.4%) low vision participants reported equal access and another 25 (48.1%) of blind and 6 (31.6%) of low vision participants reported no equal access. In a follow-up answer, 11 (21.1%) blind and 1

(5.3%) low vision participants reported accessibility problems with charts, forms, graphs, and tables. Four (7.7%) blind participants also stressed problems accessing maps for locating vaccine centers.

Ten (14.5%) respondents reported no access to telemedicine during the pandemic.

When we asked participants which currently unavailable methods of providing healthcare information they would like to become available in the future, 6 (8.4%) respondents reported wanting more accessible telemedicine platforms.

When we asked if local or regional organizations had helped participants in acquiring health-related support and services, the National Federation of the Blind (NFB) was cited as a source of COVID information by 18 (34.6%) blind and 7 (36.8%) low-vision participants.

## 8 Discussion and Conclusion

Besides the results summarized above, some participant responses also raise more basic questions about HCI and touch. When a disease of the nature of COVID-19 makes physical surfaces prohibitive due to its transmission mechanisms and social distancing among human beings a necessity, a constant vigilance of touch and proximity becomes the new sociality [25]. Researchers will have to discover what this new sociality means for interaction design and disability. How does it disable the use of all those interaction designs which were previously deemed to be accessible and accommodating? Can we invent another embodied theory of design which can overcome these limitations [26]? How does touch suddenly debilitate and discard those who were just recently enabled by the affordances of touch and tactile designs? How does "social distancing" translate to this situation when COVID-19 can suddenly colonize any random surface and the touch of the erstwhile familiar takes a deadly turn? Nabil & Girouard write: "We believe that instead of a "killer app" for deformable interfaces and wearables, the key to their success resides in creating applications and devices for specialized users. So, what is most important is to work with a variety of users, such as people with visual impairments, people with mobility impairments, people living with repetitive-strain injuries, and everyday users, to co-design and evaluate prototypes that are useful for them." [27]. We endorse robust participatory approaches that lead to co-designing with our disabled colleague designers, developers, researchers, and users with disabilities [28].

**Acknowledgments.** This study has been approved by the Internal Review Board of the University of Washington.

We thank the program chairs for inviting us to present this poster paper in the Late Breaking session of the HCII 2021 Conference. Sushil Oswal thanks Hitender for his research assistance for this paper.

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