

Guidance for Best Practices in Participatory Design Involving People with Visual Impairment

By Hyung Nam Kim 

FEATURE AT A GLANCE:

Today, a great number of people with visual impairment take advantage of mainstream technology *via* assistive technology. User involvement in the systems development life cycle contributes to addressing user needs accurately. This article presents practical strategies to facilitate participatory design approaches involving users with visual impairment. Both researchers and professional designers will benefit these practical strategies by using them as action checklists for preparing, conducting, and concluding a participatory design session ethically and responsibly.

KEYWORDS:

human factors, co-design, design approach, guidelines, disability, assistive technology

Although mainstream technology applications tend to focus on people without disabilities, we should not ignore people with disabilities who would also like to obtain the benefits of mainstream technology. Regardless of ability or disability, a great number of people use various emerging technologies today to enhance the quality of life ([Pew Research Center, 2016](#)). It is critical to make technology user friendly and accessible to users with disabilities. Yet, there is lack of attention to the ethical conduct of design practices while collaborating with participants with disabilities *via* a participatory design approach. As users know better than anyone else what they need, designers should involve a sample of users with disabilities throughout the design process. As the mental model of designers may not be identical with that of users with disabilities ([Kim, 2010](#)), they all should work together as a cohesive design team. However, users with disabilities are less likely to obtain opportunities to engage deeply in design process. For instance, user studies including users with disabilities in design activities tend to focus on summative evaluation at the end of the design process ([Kim et al., 2014](#)). User studies tend to rely on sighted but blindfolded participants and ask them to evaluate technologies on behalf of their peers with visual disabilities, that is, a simulated approach that fails to adequately reflect the true user needs ([Silverman et al., 2015](#)). Designers may incorrectly assume that user requirements are identical between users with and without disabilities. Designers may also be unfamiliar with ethical issues on how to interact with participants with disabilities ([Carlson, 2013](#)). It is important for designers to secure a deep user involvement and ethical

interactions with participants with disabilities throughout the entire design process. Without adequate understanding of disability-related design practices involving participants with disabilities, it is difficult to produce usable and accessible technology applications. Whenever I teach students or work with other professionals, they often informed me that it was not easy for them to find a comprehensively, systematically organized source of information that can practically guide them to disability research. I have been conducting disability research since 2006. I have continuously developed the technical “know-how” and put them all into this article. Thus, students and junior designers/professionals can use this article as an all-in-one reference. Thus, I share practical strategies to facilitate ethical, responsible design practices with participants who have disabilities, especially visual impairment. The following strategies are associated with three categories: *Before*, *during*, and *after* design practices. Participants in this paper refer to those with visual impairment.

BEFORE THE DESIGN PRACTICE

Finding Participants

Making Contact. People with visual impairment have difficulty in obtaining the same range of information that is accessible to sighted people *via* traditional forms (e.g., printed materials). Thus, designers should use a variety of means to inform potential participants of the participation opportunities. For example, designers prepare recruitment flyers for large-print, Braille, listserv, and newsletter, and share with representative groups of people with visual

impairment. One week after initial contact, designers may follow-up with the representative groups to explore whether any potential participants have expressed interests but should avoid excessive contacts in a short period. A list of potential places to contact includes state organizations (e.g., state library for the blind, state council of the blind, and state department of health and human services) and local/private organizations (e.g., local lions clubs, community low vision centers, assisted living facilities, and local industries who have employees with visual impairments). Potential participants who are not affiliated with state organizations may be affiliated with private/local organizations, and vice versa. Thus, it is recommended to contact both state and local/private organizations.

Gatekeepers. Designers may consider recruiting participants while collaborating with “gatekeepers” (e.g., health professionals and community organizations) who have direct access to potential participants. Yet, gatekeepers may be overly concerned about protecting community members from suspicious information (e.g., scams) and unwilling to share information with them (Becker et al., 2004). Overprotection ironically results in poor access to information such that potential participants would be unaware of the study and thus excluded from the decision whether to participate or not. There is a need to strike a balance between protection of and empowerment for participants. Therefore, designers should assure gatekeepers that their study has a scientific aim, that the protocol for participation is appropriate, that the risks to participants are minimal, and that the benefits outweigh the risks.

Time Management. Designers should assign “buffer time” into the project management, that is, extra time added into the estimate, to keep a project on track. Those community organizations may have their own advisory boards that need to review the designer’s inquiries and requests for collaboration, which would take a while. Designers should avoid scheduling a design session (e.g., an interview) in the morning because people with visual impairment may need extra time to take care of daily tasks in the morning. Designers should have a schedule flexible enough to accommodate each participant’s schedule.

Preparation of Accessible, Informed Consent

Form. Alternative formats should be available, including large-print, e-text, digital audio, and Braille, and still provide the same content as standard formats. The large-print format should use a larger font (18-point font size) and additional spacing (1.5-line spacing) (Trujillo Tanner et al., 2018). As “serif” font styles are likely to reduce the readability of print for people with low vision, the recommended print option is a “sans-serif” font (Duffy, 2021). Designers should use bold black print on a matte white or cream background, and avoid the use of graphics. To further enhance readability, a strong

contrast between the print and background is helpful, for example, a yellow translucent acetate sheet over the page, making the print “stand out” from the background.

Inclusion of Participants in the Study

Promoting Participation. Designers may consider the following strategies to promote inclusion: (1) use of appropriate sampling methods (e.g., a snowball sampling method) to locate and invite people with visual impairment (Valerio et al., 2016); (2) prepare a design method accessible to those with visual impairment (Ghodke et al., 2019) (e.g., a tangible prototyping tool (Kim et al., 2014)), and (3) modify a study protocol to better accommodate each participant (Williams & Moore, 2011).

Avoiding Coercion. Designers should adhere to ethical principles to protect the dignity, rights, and welfare of participants, including potential participants who have not yet agreed to participate in a study. Any form of coercion, manipulation, or undue influence to recruit participants is unethical (Nelson & Merz, 2002). The payment of incentives has positive effects on potential participants’ willingness to join the study and responsibly carry out a given task during the study; however, designers should not overstate them. Excessive incentives may induce potential participants to provide incorrect information in order to participate in the study when they do not meet the eligibility criteria. This will ultimately affect the integrity of the study and the validity of the data (Resnik, 2008). For example, people with “mild” visual impairment participate in a study that requires participants with “moderate/severe” visual impairment. As they are not totally blind, designers may be unable to distinguish it unless they assess the visual acuity clinically. Designers should assure potential participants that, even if they decide not to participate in the study, their decision will not affect the medical care or benefits to which they are entitled (e.g., social security disability benefits).

Active Involvement. Designers may form an advisory group that includes people with visual impairment. Those advisory group members with visual impairment could take advantage of their networks to inform as many potential participants as possible. Although advisory group members with visual impairment are not directly associated with the rules and regulations designed to protect the rights and welfare of human subjects, designers should still provide proper accommodations for them to obtain full access to physical facilities, information, and communication.

Transportation, Accessibility, and Safety. Participants are unable to drive a car and may live alone, leading to difficulty in arranging their own transportation. Designers should offer adequate transportation options (e.g., ADA paratransit services for people with disabilities). The venue must be

accessible to participants. Designers can refer to a valid guideline such as the Accessibility Guidelines for Buildings and Facilities ([US Architectural and Transportation Barriers Compliance Board, 2004](#)). Designers should keep walkways clear of objects that might cause tripping, slipping, or falling, and avoid any physical changes to venues (e.g., rearrangement of furniture, equipment, or other items) after participants have developed a cognitive map of them.

DURING THE DESIGN PRACTICE

Obtaining Informed Consent

Ensuring Voluntary and Informed Consent. Participants may prefer to receive the informed consent form in advance as they may need additional time to read it in alternative formats. [Gompel et al. \(2004\)](#) reported that the reading speed of people with visual impairment was 1.5–2 times slower than that of sighted people. [Pring \(1994\)](#) found that some Braille readers read 150 words per minute (approximately half the speed of the sighted readers) while many typically read much more slowly, for example, below 40 words per minute. Thus, a range of accommodation should be available such that participants can understand the study comprehensively and determine whether the study is consistent with their interests and preferences.

Proxy Consent. Designers may face situations in which a participant wants to include additional individuals (e.g., a sighted family member or legal guardian as a proxy). [Hendriks et al. \(2015\)](#) encountered, for example, a challenge of dealing with the conflicting viewpoints between participants with disabilities and their proxies while performing co-design sessions. Designers should use the proxies' opinions to supplement rather than replace the participants' opinions. It is essential to clearly inform proxies about the rationale for including them and their limited role in the study. Designers must obtain consent from the proxy and assent from the participant. It is critical to inform both a participant and his or her proxy that a participant who does not provide assent cannot participate in a study even if the proxy has signed the consent form. However, unless proxy consent is necessary, designers should minimize the use of proxies to respect the autonomy of participants.

Paper Signatures and e-Signatures. When participants sign the paper consent form, designers may offer a signature guide (i.e., a cardboard, metal, or plastic card that has a rectangular cut-out in the middle), which provides a raised writing line to guide the participant's signature placement. There are also alternative means, such as iMedConsentTM, a software application that helps to manage the informed consent process electronically. The Food and Drug Administration has recently issued draft guidance with regard to the use of electronic informed consent, and the regulations (21 CFR part

11) encourages a wide range of methods to create electronic signatures ([Food and Drug Administration, 2016](#)).

Interaction with Participants with Visual Impairment

Designers' Self-Introduction. As designers perform a participatory design along with participants as co-designers, it is important to have participants feel comfortable. Designers should introduce themselves by providing a business card in an alternative format (e.g., Braille or large-print). If it is a focus group, designers should introduce each participant to the group, so each participant does not feel isolated. Designers should speak respectfully about individuals with disabilities by using "people-first language" (e.g., people who have visual disabilities) instead of "disability-first language" (e.g., visually impaired people). Designers may use the words "see" or "look" when communicating with participants, as these words are part of everyday conversation and are not considered offensive ([Ability360.org, 2019](#)).

Provision of Assistance. If a participant appears to need help (e.g., navigation), designers should ask first to confirm it. Designers should not unexpectedly grab or pull a participant's body, which may lead to accidents or embarrassment. After the participant accepts the offer of assistance, the designer will let the participant grasp the designer's arm just above the elbow, which makes it easier for the participant to feel the designer's movement. People with visual impairments typically follow the guide by walking a half step behind; thus, the designer should walk at a normal pace and stop for any objects (e.g., curbs). Participants would appreciate specific and clear directions and directional language. If participants need help with balance, designers should help them locate a handrail or the back of a chair. As a guide dog must focus on assisting the participant, designers should walk on the side opposite the dog and not touch the dog because any distraction would keep the dog from doing so, possibly putting the participant in danger. As a white cane is part of the participant's personal space, designers should not touch or move it even when the participant puts it on the floor.

Entering and Exiting a Room. If any new individual enters or exits a room, designers should inform the entire group of participants. When the designer needs to step out even for a few minutes, the designer should still inform the entire group so that they do not continue the conversation. When participants need to wait in a room without the designer's presence, the designer should help participants stay near a certain landmark (e.g., furniture, a window, or a wall) that facilitates their orientation and mobility. When the designer needs to talk to a particular participant, it is essential to address the participant by saying his/her name, or by mentioning his/her clothing, seat location, or something else that identifies him/her.

Table 1. Action checklists for participatory design with participants with visual impairment.

Design activities		Contexts	Actions
1. Finding participants	1.1 Making contact	People with visual impairment have difficulty in obtaining the same range of information that is accessible to sighted people via traditional forms	<p>Prepare recruitment flyers in alternative formats</p> <p>Collaborate with representative groups who work for people with visual disabilities</p> <p>Avoid excessive contacts</p>
	1.2 Gatekeepers	Gatekeepers may be overly concerned about protecting community members from suspicious information (e.g., scams) and unwilling to share information with them	inform gatekeepers fully about the study, e.g., scientific aims; detailed protocols of data collections and analyses; and risks and benefits of participations
	1.3 Time management	Community organizations may have their own advisory boards that need to review the designer's requests for collaboration, which would take a while. Participants may also have busy schedules	<p>Assign "buffer time" to keep a project on track</p> <p>Be flexible to accommodate participants' busy schedules</p>
	1.4 Preparation of accessible, informed consent forms	The large-print consent form should provide the same content as standard print but should still be readable	<p>Use the following formats for good readability</p> <p>18-point font size</p> <p>1.5-line spacing</p> <p>Sans-serif font</p> <p>Bold black print on a matte white or cream background</p> <p>No graphics</p> <p>Strong contrast between the print and background</p>
2. Inclusion of participants	2.1 Promoting participation	It is often difficult to include research participants but also work with them in the participatory design session due to challenges caused by visual impairment	<p>Recruit participants using snowball sampling</p> <p>Use of design methods accessible to participants with visual impairment (e.g., tangible prototyping tools)</p> <p>Modify a study protocol to accommodate participants with different needs and challenges caused by different vision status</p>
	2.2 Avoiding coercion	Designers should adhere to ethical principles to protect the dignity, rights, and welfare of participants	<p>Avoid excessive incentives</p> <p>Assure participants that there would be no penalty for withdrawal from the study and not affect their medical care and benefits</p>
	2.3 Transportation, accessibility, and safety	Participants are unable to drive a car and may live alone, leading to difficulty in arranging their own transportation. The venue for a study must be safe and accessible to participants	<p>Offer adequate transportation options</p> <p>Keep walkways clear of objects</p> <p>Avoid any physical changes to venues after participants have developed a cognitive map of them</p>

(Continued)

Table 1. (Continued)

Design activities		Contexts	Actions
3. During the design practice	3.1 Informed consent	The reading speed of people with visual impairment is much slower than that of sighted people as they should read in alternative formats (e.g., Braille and large-print) or use assistive technologies	Provide potential participants the informed consent form in advance (a few days before the study)
	3.1.1 Ensuring voluntary and informed consent		
	3.1.2 Proxy consent	A participant may want to include additional individuals (e.g., a sighted family member or legal guardian as a proxy)	Use the proxies' opinions to supplement rather than replace the participants' opinions
			inform proxies clearly about the rationale for including them and their limited role in the study
			Obtain consent from the proxy but also assent from the participant
			Minimize the use of proxies to respect the autonomy of participants, unless proxy consent is necessary
	3.1.3 Paper-signatures and e-signatures	While some participants prefer a paper-based consent form, others may prefer an electronic consent form	Offer a signature guide (i.e., a card with a rectangular cut-out in the middle) to provide a raised writing line to guide the participant's signature
			Offer options to complete the informed consent process electronically
	3.2 Interaction with participants	As designers perform a participatory design along with participants as co-designers, it is important to have participants feel comfortable	Introduce the design team by providing a business card in an alternative format (e.g., Braille)
	3.2.1 Introduction		Speak respectfully about individuals with disabilities by using "people-first language"
	3.2.2 Provision of assistance	Not all people with visual disabilities will need and want assistance although they appear to be seeking help	Confirm whether participants need help before providing it
			Let participants grasp the designer's arm just above the elbow
			Walk at a normal pace and stop for any objects by providing specific and clear directions and directional language
			Help participants to locate a handrail or the back of a chair when they need help with balance
			Walk on the side opposite a guide dog and do not touch the dog
			Do not move a white cane when the participant puts it on the floor
	3.2.3 Entering and exiting a room	Designers may conduct a participatory design session with a single participant (via an interview) or a group of participants (via a focus group)	inform everyone in the focus group when a person enters or exits a room
			Help participants stay near a landmark (e.g., wall) for their orientation and mobility when designers step outside Address a participant by saying his/her name or mentioning his/her clothing, seat location, or something else to identify him/her
	3.3 Interview	Designers may use a notepad or a recording device to capture participants' comments and feedback	Keep a pen and paper handy to draw a quick sketch or take a note
			Keep participants updated on the recording status
	3.3.1 Recording		Bear in mind that participants cannot see designers taking a note (or sketching) slowly so that they do not wait for designers, and designers should keep recording during the interview
	3.3.2 Sensitive questions and reactions	In-depth interviews that deal with sensitive topics may bring up unpleasant memories	Provide contact information of counselors who are specially trained to aid people with disabilities instead of general counselors
			Complete a training program to learn how to avoid provoking distress, recognize signs of distress, and use measures to diffuse it
	3.3.3 Guests and private interviews	Participants may arrive with guests (e.g., sighted family or friends) who wait until the participation ends	Set up the interview in such a way the guest is available, but not present nearby to maintain the confidentiality
	3.3.4 Interviewers with empathy	Interviewers play an important role in obtaining the cooperation of participants, helping to clarify interview questions, and motivating participants to provide complete and accurate answers	Develop or enhance empathy to gain deeper insights into the participants' needs and concerns and apply this knowledge to the designs
	3.3.5 Sample size	In a large group, participants with visual disabilities could easily be confused by the communication flow, ending up with a limited opportunity to share insights	Avoid a large sample size
			include additional assistants to facilitate the session when designers cannot divide a large group into several small groups
	3.3.6 In-Person versus virtual data collection	Participants may consider the designer as a stranger and feel uncomfortable with being at home alone when "the stranger" comes in for an interview	Have a phone conversation with participants prior to the interview day, so they become familiar with the interviewer's voice
			Give participants another phone call just before knocking on the door, and the phone number used should be identical to the earlier call
			As alternative approaches, a remote or a virtual data collection would contribute to reducing anxiety and making participants feel safe
	3.3.7 Exit interview	A design session ends with an exit interview to hear final thoughts of participants and allow them to ask any questions that they may have	Remind participants of how the interview data will be analyzed and how their personal information will be protected although the informed consent form must include all the necessary information in alternative formats
4. After the design practice		Although a study ends, designers may need to maintain a good relationship with participants for future research. As it is often difficult for designers to recruit participants who meet the inclusion criteria (e.g., particular disabilities), designers can reinvite them	Share research findings (e.g., his/her performance compared to other interviewees); serve as a guest speaker for the community organizations for people with visual impairment; and participate in their regular meetings

Interview

Recording. Designers should keep participants updated on the recording status (e.g., “The recorder is turned off during the break”). However, participants may provide additional information (i.e., design insights) even during the break; thus, designers should always have a pen and a piece of paper to take brief notes. Participants cannot see designers taking a note slowly and participants may not wait or speak slowly; thus, designers should consider keeping the recording device on hand.

Sensitive Questions and Reactions. In-depth interviews that deal with sensitive topics may bring up unpleasant memories. An interview protocol should include the contact information of appropriate counseling supports. Yet, designers should refer participants to counselors who are specially trained to aid people with disabilities (Haj, 1991). Designers may also consider completing a training program where they learn interview skills that do not provoke distress, recognize signs of distress, and use measures to diffuse it (Corbin & Morse, 2003).

Guests and Private Interviews. Participants may arrive with guests (e.g., sighted family or friends), and the guests may wait until the participation ends. If the study requires a private session, designers should set up the interview in such a way that the guest is still available but not present nearby, which will help to maintain the confidentiality of the study process.

Interviewers with Empathy. Interviewers play an important role in the data collection process (e.g., elicitation of user needs) as they can contribute by obtaining the cooperation of participants, helping to clarify interview questions, and motivating participants to provide complete and accurate answers. A highly qualified interviewer meets the following criteria: a clear, logical mind; an ability to listen; and a skill to establish a good rapport and to empathize (Ritchie et al., 2013). Empathy can particularly be pertinent to interviews with participants with disabilities as empathy refers to the ability to recognize, understand, and share the thoughts and feelings of another person (Suri, 2001). Interviewers should develop or enhance empathy to gain deeper insights into the lives and experiences of participants and apply this knowledge to the designs that meet user needs.

Sample Size. With regard to an ideal sample size for a focus group, different guidelines are available in the literature, for example, four to eight participants (Kitzinger, 1995); five to eight participants (Krueger & Casey, 2014); and six to twelve participants (Morgan, 1997). However, designers should avoid a large sample size if the group includes participants with disabilities. Vision is one of the primary senses in the perception of nonverbal communication and helps to understand and facilitate the flow of communication (e.g., turn taking) especially in a large group. In a large group,

participants with visual disabilities could easily be confused by the communication flow, ending up with a limited opportunity to share insights. When designers cannot divide a large group into several small groups, the interview session should include additional assistants to facilitate the session.

In-Person Versus Virtual Data Collection. A design session can take place in various venues, including participants’ own environment (e.g., home) that would be convenient for them as they would not need to travel but feel comfortable, probably leading to more reliable data. A designer ought to find an opportunity to have a phone conversation with participants prior to the interview day, so participants can become familiar with the designer’s voice. Participants rely significantly on their familiarity with the designer’s voice to distinguish it from a stranger, especially when a door is being opened for them. The designer may give participants another phone call just before knocking on the door, and the phone number used should be identical to the earlier call. Participants may still consider the designer as a stranger and feel uncomfortable with being at home alone when “the stranger” comes in for an interview, especially under the condition that they cannot see. Alternatively, the designer may consider a virtual data collection option (e.g., telephone interviews) to reduce anxiety and make participants feel safe. Another option is a remote study in which the designer provides participants with specific instructions, and participants complete the data collection by themselves and send the results back to the designer.

Exit Interview. Before completing the study, designers should remind participants of how the interview data will be analyzed and how their personal information will be protected although the informed consent form should already include all the necessary information in alternative formats.

AFTER THE DESIGN PRACTICE

As it is often difficult for designers to recruit participants who meet the inclusion criteria (e.g., particular disabilities), designers should maintain a good partnership with those who participated in the study in the past as they are likely to participate again and also introduce new potential participants for future studies. Designers may recontact participants to share the study results; serve as a guest speaker for the community organizations for people with visual impairment; and participate in their regular meetings.

CONCLUSION

I have presented practical strategies to facilitate the participatory design involving participants with visual impairment, which will contribute to respecting the dignity, autonomy, equality, and diversity of all those engaged in the participatory design processes. Although some of the strategies may be found from other resources, those resources are typically scattered, unorganized, and fragmented. I

summarized the practical strategies in Table 1 that serves as an all-in-one resource and provides an organized collection of essential skills and knowledge, immediately applicable to design sessions. For broader impacts, Table 1 could be accordingly amended to accommodate other individuals who have different needs. For participants with hearing impairments, the recommendations in Table 1 should be accordingly customized by focusing on a sense of vision instead of a sense of hearing. For example, the consent form may include visual information such as symbols, pictures, or diagrams to enhance understanding. Participants may also receive a video file or hyperlink where they can watch a set of activities they are anticipated to perform during the interview. When recruiting participants, text-based approaches are recommended such as letters, emails, and text messages. Interviewers should be proficient at sign language or hire a professional interpreter. Alternatively, a real-time translation software (e.g., Google's Live Transcribe mobile app) may be employed. Interviewers should make sure that the venue is equipped with visible safety measures, such as a fire alarm with flashing lights.

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ORCID iD

Hyung Nam Kim  <https://orcid.org/0000-0003-1443-2122>

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Author Biographies

Hyung Nam Kim is an Assistant Professor in the Department of Industrial and Systems Engineering at the North Carolina A&T State University. He earned his PhD in Industrial and Systems Engineering from Virginia Tech. His research interests include human factors, human-computer interaction, health informatics, and safety.

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