# Developing the Aging Concerns, Challenges, and Everyday Solution Strategies (ACCESS) Study

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#### **EXECUTIVE SUMMARY**

There are growing numbers of older adults with long-term sensory and mobility impairments who are a part of a population described as "aging with disability" (Putnam, Molton, Truitt, Smith & Jensen, 2016; Vebrugge & Yang, 2002). Very little is known about the everyday task challenges experienced by these individuals as they age, and experience the associated normative changes, such as declines in vision, cognition, and motor functioning (Harrington, Mitzner, & Rogers, 2015). Technology holds great potential to support everyday activities to minimize or prevent disability among individuals with long-term impairments as they age (Agree, 2014). For such technological advances to be successful in supporting individuals aging with impairment, we must understand the nature of their specific needs and challenges (Scherer, 2005).

The RERC TechSAge is a five-year, multidisciplinary center dedicated to understanding the needs of, and developing supportive technologies for, individuals aging with pre-existing, long-term sensory and mobility impairments. TechSAge is comprised of research, development, and training projects made possible by a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (Department of Health & Human Services, Administration for Community Living; Grant # 90RE5016-01-00). The overarching goal of the TechSAge User Needs Research project is to provide a need-based scientific foundation that is necessary to guide development of integrated technology and advance fundamental understanding of general needs of older adults with long-term impairments.

As part of the TechSAge User Needs research project, investigators developed a large-scale, mixed method study investigating user needs of individuals aging with impairment. The Aging Concerns, Challenges, and Everyday Solution Strategies (ACCESS) study provides a

comprehensive user needs assessment for older adults with long-term vision, hearing, or mobility impairments. ACCESS is a two-part study comprised of questionnaires (e.g., demographics, health, functional limitations) and an in-depth interview assessing challenges with a range of daily activities and current responses to those challenges, including strategies for overcoming them. Data will provide the evidence base to develop a taxonomy of everyday support needs and provide guidance for the design of supportive technologies for this understudied population. This technical report provides an overview of the ACCESS Interview Study with regard to its development, procedures, and materials.

# 1. INTRODUCTION

Advances in healthcare, rehabilitation, and technology are enabling individuals with impairments to live longer lives than ever before (Institute of Medicine, 2007). A recent U.S. Census Report revealed that nearly 37.4% of older Americans (over age 65) reported having one or more disabilities, including impairments in mobility (63.8% of those with disabilities), hearing (41.5%), and vision (18.8% U.S. Census Bureau 2016). Despite the prevalence of older adults with sensory and mobility impairments, very little is known about the segment of this population who acquired their impairments in early or mid-life, said to be "aging with disability" (Putnam, Molton, Truitt, Smith & Jensen, 2016; Vebrugge & Yang, 2002). In the U.S., an estimated 12-15 million adults are aging with impairments that began prior to age 40 (LePlante, 2014). As people live longer with significant impairments acquired in early, middle, or late life, they are experiencing a variety of unique and negative health outcomes, including secondary conditions related to the underlying impairment and additional age-related declines that put them at risk for greater disability.

Technology holds great potential to support individuals aging with long-term sensory and mobility impairments in maintaining daily activities in the home and community so they can age in place (Mitzner, Sanford, & Rogers, 2018). To effectively design technologies to support individuals aging with impairment, we must understand and consider their specific needs and challenges. (LePlante, Kaye, Kaneg, & Harrington, 2004; Peek, Wouters, Luijkx, & Vrihoef, 2016; Scherer, 2005). Furthermore, effective technology design requires an understanding of the context in which the support will be provided, and individual abilities, preferences, cultural practices, and privacy concerns.

One of the most well-known models of successful aging, the Selection, Optimization and Compensation (SOC) Model provides a broad-based theoretical perspective from lifespan developmental psychology for understanding user needs for people in our target populations (Baltes 1997). The SOC model describes how individuals adapt to developmental challenges across the life span via the processes of selection, optimization, and compensation. *Selection* refers to choosing a subset of goals or developing new attainable goals (e.g., maintaining independence when limited resources reduce the number of goals attainable). *Optimization* refers to investment of time and energy to behaviors that support chosen goals. *Compensation* refers to regulating loss through substitute mechanisms to maintain activity. The SOC model has been successfully applied to understand geriatric care management (Donnellan 2015) and aging in place and (Kelly, Fausset, Rogers, & Fisk, 2014). In addition to understanding how individuals are adapting to normative age-related changes, the SOC model can be used as a framework to understand the challenges and adaptive strategies of individuals aging with long-term impairment (Remillard, Fausset, & Fain, 2017).

Guided by the SOC model, the Aging Concerns, Challenges, and Everyday Solution Strategies (ACCESS) study is a large-scale, mixed-method study investigating user needs of individuals aging with impairment. The ACCESS study aims to understand the nature and distribution of task performance problems with everyday activities for older adults with long-term vision, hearing, or mobility impairment. In addition to activity challenges, the study explores the various responses individuals in these three distinct populations have to the challenges, including strategies they employ to manage them. The ACCESS study utilizes both quantitative (questionnaires) and qualitative (structured interview) methods to assess perceptions of task difficulty and the nature of participants' challenges and responses. The study will include 60 participants (aged 60-79) in each of the three target populations (blind/low vision, Deaf/hard of hearing, mobility impaired); target total n = 180). Data will provide insights into unmet needs among older adults with long-term sensory and mobility impairments and will provide guidance for the design of supportive technologies for this understudied population.

# 2. DEVELOPMENT

# 2.1. Preliminary Work

The development of the ACCESS Study entailed a number of preliminary efforts to inform the content and design of the study. As an initial step, TechSAge researchers conducted an archival analysis, reviewing pertinent survey data from large-scale studies that included activity challenges faced by individuals aging with functional limitations and their technology use (Harrington, Mitzner, & Rogers, 2015). The archival analysis revealed that very little is known about older adults with pre-existing impairments specifically; available statistics and resources were limited to the broader population of older adults with impairments and did not account for age of impairment onset. Moreover, the sparse information regarding difficulty in

task performance and use of assistive technology among older adults with impairments typically focused on select Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs) and failed to capture more enhanced activities, such as leisure, in which older adults spend a large proportion of their time (Rogers, Meyer, Walker, & Fisk, 1998). Findings confirmed the need to comprehensively explore everyday task challenges, current responses and strategies, and unmet support needs for this understudied population.

Second, to inform the development of the interview, it was necessary to understand more about the range of challenges in everyday activities experienced by the three target populations: older adults with long-term vision, hearing, or mobility impairments. To gain initial insights on challenges experienced across and between groups, we conducted interviews with Subject Matter Experts (SMEs) with personal and/or professional experiences with older adults with sensory and mobility impairments (e.g., caregivers, medical professionals; Preusse, Remillard, Singleton, Mitzner & Rogers, 2016). SMEs gave their perspectives on challenges experienced by these populations, with specific emphasis on identifying challenges related to technology, access to community resources, and housing. A thematic analysis revealed challenges that were unique for each impairment group as well as those that were cross-cutting. Lastly, given the lack of available information on technology use among Deaf older adults, we surveyed Deaf older adults (n = 109) about their use of and experiences with technologies, including assistive technologies for persons with hearing loss and general, everyday technologies (Singleton, Remillard, Mitzner, & Rogers, 2018). Each of these preliminary efforts directly informed the content of the ACCESS study materials and/or design of the study structure.

Guided by the SOC model, the structured interview study was designed to assess detailed information about participants' challenges with everyday activities and their responses to those

challenges, including the various strategies they use to overcome those challenges (see section 3.3 for a description of the interview). The interview script was developed in English and was first evaluated with a participant in the vision group and one in the mobility group. Through this process, the script was refined to improve question clarity and the flow of the interview. Once the English script was finalized, a parallel ASL translation of the script was developed and tested with two Deaf older adult participants.

The structured interview study also included questionnaires to assess a variety of participant characteristics including: demographics, health, functional abilities, limitations, use of aids/services, and the nature of their vision, hearing, or mobility impairment. Questionnaires included the ACCESS Questionnaire, Supplemental Questionnaires, and TechSAge Minimum Battery (see section 3.2 for a description of the questionnaires). Prior to launching the study, all the materials (structured interview script and questionnaires) were evaluated by materials testers, including student research assistants, and individuals from each target population (older adults with vision, hearing, and mobility impairments). Through this process, materials were refined in terms of formatting and question clarity. A Manual of Operations (MOP) was developed to assist interviewers with administering all study materials in the proper order (see Appendix A for complete MOP).

#### 2.2. Accommodations

The study was designed with flexible administration options to accommodate participants with sensory impairments. All forms and questionnaires were made available to participants based on their preference. In addition to the standard paper consent form, participants had access to an audio recording and an ASL video parallel to the consent form language. The paper questionnaires were made available as online surveys, which were tested for screen reader

compatibility. Participants also had the option to have a researcher administer the questionnaires by telephone or videophone.

From a research design perspective, the Deaf community is quite distinct from the other two participant populations. While their hearing loss is very much part of their identity, so is their preferred use of American Sign Language. The other two participant groups are users of English and thus can be interviewed directly over the phone or in person by our Englishspeaking research team. Deaf participants, however, would have had to be interviewed by our English-speaking team through a sign language interpreter. The research team was concerned that following the same interview script with all participants in the study would entail the risk of much being "lost in translation" for Deaf participants. To ensure authenticity and cultural/linguistic appropriateness, it was decided that interviews with Deaf older adult participants would be conducted in ASL by interviewers who are also Deaf. The team agreed that an ASL-ASL dyad would most closely approximate the English-English dyad used with the other participant groups.

One of the project investigators, who is a native user of ASL, worked with native-signing sign language interpreters to develop an ASL translation of the script. The ASL script was a modified version of the English script with sentence structure and phrases best suited for direct ASL translation. A video was made of the ASL script delivery for training purposes. We identified three Deaf older adults (over age 50, ASL-fluent) who expressed interest in our research and we invited them to conduct ACCESS interviews with our team. All three interviewers participated in a half-day training on the study procedures and several follow-up videophone calls with our team to respond to remaining questions or script fidelity challenges. Each Deaf interviewer completed the online CITI training for research with human subjects (in

English; unfortunately, of the many languages that CITI training is offered in, ASL is not one of them). The ASL script was further refined based on feedback from our trained Deaf interviewers.

# 3. MATERIALS 3.1. Screening Script

The screening script (Appendix B) was developed to orient potential participants to the goals of the study, determine participant eligibility, and assist researchers with scheduling and materials distribution for eligible participants. The script begins with a brief overview of the study, compensation, and the purpose of the screening call. Participants are asked to provide their contact information (e.g., name, phone number, email) as well as date of birth and primary language. Then, all potential participants are asked screening questions about their vision, hearing, and mobility. Participants are asked whether they self-identify with each impairment group (blind or low vision; mobility impaired; Deaf or hard of hearing). If participants answer yes to any of the impairment groups, they are asked open-ended follow-up questions regarding the nature of the limitation, the age at which it began, and any supportive aids they use. If participants identify as belonging to more than one of these groups, they are asked to select a primary group with which they identify most. Participants who meet the eligibility criteria are then asked about their preferences to complete the interview and questionnaires and are scheduled for an appointment for the interview.

# 3.2. Questionnaires

Questionnaires featured in the ACCESS study materials incorporate a number of existing measures, depicted in Table 1.

Table 1. Source Materials Included in the ACCESS Interview Study

Questionnaire	Page and Question #	Measure	Source Citation				
TechSAge Minimum Battery		Demographics; health; functional capabilities and limitations; technology experience	Gonzalez, E. T., Mitzner, T. L., Sanford, J. A., & Rogers, W. A. (2016). <i>TechSAge minimum battery: Overview of measures</i> (TechSAge-TR-1601). Atlanta, GA: Georgia Institute of Technology, Rehabilitation Engineering Research Center on Technologies to Support Successful Aging with Disability.				
ACCESS Questionnaire	Pgs. 1-4 (#1 – 15)	Life space	Baker, P.S., Bodner, E. V., Allman, R. M. Measuring life-space mobility in community-dwelling older adults. Journal of the American Geriatrics Society, 2003; 51: 1610–1614				
	Pg. 5 (#1-4)	Technology adoption style	Questions based on: Parasuraman, A. (2000). Technology readiness index (TRI): A multiple-item scale to measure readiness to embrace new technologies. <i>Journal of Service Research</i> , 2, 307-320. doi: 10.1177/109467050024001				
	Pg. 6 (#1- 13)	Quality of life	Logsdon, R. G., Gibbons, L. E., McCurry, S. M., & Teri, L. (1999). Quality of life in Alzheimer's Disease: Patient and caregiver reports. Journal of Mental Health and Aging, 5(1), 21-32.				
Supplemental Questionnaires							
Vision	Pg. 1-2 (#3-5)	Types of vision impairment, visual acuity, & reading ability	Questions based on: International Council of Ophthalmology. (2002). Visual standards: Aspects and ranges of vision loss with emphasis on population surveys (ICO Report). Sydney Australia: Colenbrander, A. Retrieved from: <a href="http://www.icoph.org/resources/resources_detail/63/ICO-Resolution-on-Visual-Terminology.html">http://www.icoph.org/resources/resources_detail/63/ICO-Resolution-on-Visual-Terminology.html</a> Accessed July 20, 2016				
Deaf and Hard of Hearing	Pg. 1 (#3)	Types/descript ors of hearing loss	Questions based on: American Speech-Language-Hearing Association. (2015) Audiology Information Series: <i>Type, degree, and configuration of hearing loss</i> . Retrieved from: <a href="https://www.asha.org/aud/pei/">https://www.asha.org/aud/pei/</a>				
	Pg. 2 (#4)	Degree of hearing loss	Questions based on: Clark, J. G. (1981). Uses and abuses of hearing loss classification. <i>Asha</i> , 23, 493–500				
Mobility	Pg 1. (#4)	Degree of mobility loss	Questions based on: Palisano, R., Rosenbaum, P., Walter, S., Russell, D., Wood, E., & Galuppi, B. Development and reliability of a system to classify gross motor function in children with cerebral palsy. <i>Dev. Med. Child Neurol.</i> 1997, 39, 214–223.				

# 3.2.1. TechSAge Minimum Battery

Developed as a part of RERC TechSAge, the TechSAge Minimum Battery is a questionnaire designed to collect a range of background information about research participants across studies. The Minimum Battery is a self-report 168-item questionnaire composed of a core set of measures including: demographics; health; sensory and mobility capabilities; technology use; and experience. Full details on source materials and content of the assessment are in the TechSAge Minimum Battery technical report (Gonzalez, Mitzner, Sanford, & Rogers, 2016).

# 3.2.2. ACCESS Questionnaire

The ACCESS questionnaire (40-items) was developed specifically for this study to capture additional measures of interest including: life space, technology adoption style, quality of life, transportation, and utilization of formal care and services (see Appendix C). The Life Space Assessment (LSA) measures the extent and frequency of movement of individuals across different levels of life space (i.e., in the home, outside the home, in neighborhood, in town, and out of town) and whether or not any aids or human assistance is needed to get there (Baker, Bodner & Allman, 2003). The Technology Adoption Style section includes four locally developed questions that were designed to reflect factors within the Technology Readiness Index (TRI), which is a 36-item scale that assesses an individual's willingness to adopt and embrace emerging technologies (Parasuraman, 2000). Respondents are asked to think about when a new technology goes on the market and rate their agreement with four statements using a 5-point scale (1 = strongly disagree, 2 = disagree, 3 = neither agree nor disagree, 4 = agree, 5 = strongly agree). The Quality of Life section includes 13 questions from the Quality of Life in Alzheimer's Disease questionnaire (QOL-AD; Logsdon, Gibbons, McCurry, & Teri, 1999). Respondents

rated different aspects of their quality of life using a 4-point scale (1 = poor, 2 = fair, 3 = good, 4 = excellent).

The questionnaire includes four locally developed questions about Transportation that assess respondents' driving status, what types of transportation they have access to, what types they use, and how frequently they use them. Lastly, the Formal Care and Services section (8-items) includes locally developed questions that assess the respondents use of services in the past month (e.g., formal caregiver assistance with in-home personal care, free or reduced cost meal centers or delivery programs, visiting nurse assistance). For each service, there is a follow-up question to gauge how often the service is used based on a 5-point scale (1 = daily, 2 = weekly, 3 = monthly, 4 = less than once a month, 5 = never).

# **3.2.3.** Supplemental Questionnaires

In addition to the two self-report questionnaires, the interviewer administers a brief supplemental questionnaire that corresponds to the participant's respective impairment group: 1) blind or low vision, 2) mobility impaired, and 3) Deaf or hard of hearing. These three supplemental questionnaires capture information about the nature and degree of participants' impairment (see Appendices D-F). If participants report having more than one impairment that began prior to age 50 in the initial screening, they are administered all pertinent supplemental questionnaires. For all three versions, respondents are first asked to select the primary cause of their impairment from a series of choices (condition or illness; accident or event; unknown). They are then asked to describe the cause in further detail and the approximate age their impairment began. The remaining items on each questionnaire assess the characteristics and degree of impairment in more detail.

The Vision questionnaire (see Appendix C) contains three additional questions based on the standards for aspects and ranges of vision loss set forth in the International Council of Ophthalmology (ICO) Resolution on Visual Terminology (ICO, 2002). Blind/low vision participants are presented with a list of vision impairments and asked to select all that apply to them (e.g., blurred vision, color blindness). This question includes the option "other", wherein participants can specify any other types of vision impairment they experience. Next, participants are asked a multiple-choice question about their visual acuity range. The visual acuity ranges, presented in U.S. notation form, map onto the ICO classification of vision loss ranges. For example, the range 20/200 to 20/400 indicates Severe Visual Impairment. Lastly, to assess reading capabilities, participants are asked how well they can read, considering their better eye with any correction. This question is followed up by reading ability options that map onto the ICO classification of vision loss ranges. Options range from "can read small print" to "no visual reading (use of Braille or other non-visual sources)".

The Deaf and Hard of Hearing questionnaire contains two additional questions that assess the characteristics and degree of hearing loss experienced by the participant (see Appendix D). First, participants are asked a four-item question about which types of hearing loss they have. For each item, participants select one of the two opposing options that are common descriptors associated with hearing loss (American Speech-Language-Hearing Association, 2015). For example, in the first item, participants select whether their hearing loss is in both ears (bilateral) or in one ear only (unilateral). Next, participants are asked a multiple-choice question to select their range of hearing loss (in decibels) for each ear. The provided decibel ranges are commonly used to classify degree of hearing loss on a spectrum of "normal" to "profound" (Clark, 1981). If

participants did not know their decibel loss, we obtained their layperson's description (e.g., "totally deaf" or "hard of hearing").

In the Mobility questionnaire (see Appendix E), participants are presented with a list of mobility impairment types and asked to select all that apply (e.g., loss of balance, motor control difficulty). The list of mobility impairment types was locally developed with input from experts in applied physiology. As a final question, mobility participants are asked about their degree of mobility loss by identifying the option that best describes their ability to ambulate (e.g., I can walk with a cane, I can move with a wheelchair). Questions were locally developed, but modeled after the Gross Motor Functional Classification System (GMFCS), which is a five-level, ordinal grading system to describe the gross motor function of an individual with Cerebral Palsy based on their abilities, use of aids, and assistance from others (Palisano et al., 2007).

# 3.3. Structured Interview Guide

A structured interview guide was developed to elicit participants' challenges with everyday activities as well as the strategies they employ to overcome those challenges. For complete interview guide, see MOP (Appendix A). The interview begins with an icebreaker question wherein participants are asked an open-ended question: "Imagine you have 1 hour to do any one thing...What favorite activity or hobby would you do with this time?" After participants respond, they are informed that the interview will focus on their daily activities and particularly how they may have changed the way they do activities as they have gotten older. The interview covers six categories of topics: 1) Activities Outside the Home, 2) Things you Do Around the Home, 3) Shopping and Finances, 4) Transportation, 5) Managing Health, and 6) Basic Daily Activities. For each category, there is a rating activity followed by open-ended interview questions.

Participants are asked to rate different topics of activities based on how difficult it is for them to perform the activities using a 3-point scale (1 = not at all difficult, 2 = a little difficult, 3)= very difficult, or N/A = not applicable). For each category, there is a list of 5-8 topics of activities developed by the research team and driven by findings from our Subject Matter Expert study (Preusse, Remillard, Singleton, Mitzner, & Rogers, 2016). Table 2 displays a sample list of topics for the Activities Outside the Home category. The interviewer uses a worksheet to document the difficulty ratings for each topic (See Appendix G). Participants are instructed to give ratings based on the way they currently do the activity now, including any help or support they receive. Once all ratings have been provided, the interviewer reviews the worksheet to identify the topic with the highest difficulty rating, which will be the subject of follow-up, openended questions. If multiple topics are rated equally difficult, the interviewer asks the participant to select the one that creates the most challenges for them. In situations where all topics were rated as "not at all difficult", the follow-up questions about the most difficult topic of activities are skipped.

Table 2. Sample list of topics for the Activities Outside the Home category

	Topics: Activities Outside the Home
1.	Doing activities with a group or organization (for
	example, club meetings, games, classes)
2.	Going to entertainment events or activities (for
	example, movies, restaurants, sporting events)
3.	Participating in religious services and activities
4.	Visiting family and friends (for example, vacation)
5.	Working, volunteering, or participating in other
	civic activities

Following the rating activity, there are eight open-ended questions (Table 3). These questions were designed to capture how participants are adapting their activity routines and managing challenges. The first three questions ask about the category overall. Questions 4-8 are follow-up questions about the most difficult topic of activities identified in the rating activity.

Table 3. Sample interview questions for the Activities Outside the Home category

- 1. How has the way you do activities outside of the home changed as you have gotten older, if at all?
- 2. How has the frequency with which you do **activities** outside of the home changed as you have gotten older, if at all?
- Are you satisfied with your ability to engage in activities outside of the home?
- Thinking about [insert most difficult topic], what aspect or part of this creates the most challenges for you?
- How do you handle this challenge?
- 6. Do you use any sort of devices, tools, or technologies to help you with this {task/activity}?
- 7. Do you use any of your own methods or things you came up with to help you do that {task/activity}?
- 8. Do you get help from anyone (for example, services, care-providers, family members) to do that {task/activity}?

Once the questions for all six activity categories have been administered, the interviewer asks four wrap up questions to conclude the interview. First, participants are asked to think about all the different activities they do and identify the activity that has been most challenging for them as they have gotten older. As a follow-up question, participants are asked, "How does that make you feel?". Next, participants are asked to share which activity they think they have dealt with most successfully and how that makes them feel. This question was designed to elicit participants' thoughts on particular strategies or methods that they are proud of and/or feel are most effective. The final two questions were designed to end the interview, which is largely focused on difficulties and challenges, on a positive note. Participants are asked, "How do you think having a [vision/hearing/mobility] impairment for a long period of time has helped you grow stronger to face challenges as you age?". In the final question, participants are asked to share advice for other people with a [vision/hearing/mobility] impairment as they age.

# 4. PROCEDURES

# 4.1. Recruitment and Screening

To be eligible for this study, participants must be between the ages of 60 and 79 and have a vision, hearing, or mobility impairment that began prior to age 50. There are additional inclusion criteria specific to each impairment group (Table 4). Vision participants must self-identify as Blind or Low Vision, operationally defined as being unable to see or having serious difficulty seeing even when wearing glasses or contact lenses. Participants in the Hearing impairment group must self-identify as Deaf or hard of hearing and use American Sign Language (ASL) as their primary language for communication. Mobility participants must self-identify as having a mobility impairment and either use a mobility aid or have serious difficulty walking or climbing stairs. All participants must live in the Unites States and be able to complete the interview in English or ASL. Participants receive \$30 USD compensation for completing the questionnaires (1 hour) and interview (1-1.5 hours).

Table 4. Inclusion Criteria

	Additional Inclusion Criteria for each group				
General Inclusion Criteria	Vision	Hearing	Mobility		
Between the ages 60-79	Self-identify as being Blind or Low Vision*	Self-identify as Deaf or Hard of Hearing	Self-identify as having a mobility impairment		
Have had the vision, hearing or mobility impairment prior to age 50	Unable to see OR Have serious difficulty seeing even when wearing glasses or contact lenses	Use American Sign Language (ASL) as primary language for communication	Use a mobility aid (i.e., cane, crutches, wheelchair, walker, or scooter)  OR  Have serious difficulty walking or climbing stairs		
Able to complete interview in English or American Sign Language					
Live in the United States					

<sup>\*</sup> Low vision refers to a loss of vision that may be severe enough to hinder an individual's ability to complete daily activities, while still retaining some degree of useable vision.

Individuals who express interest in the study are administered the screening script to determine eligibility (see Appendix A). For participants with vision and mobility impairments, the screening questions are asked over the phone. Deaf participants are either asked the screening questions over email or via videophone by one of the Deaf interviewers. Videophone is a common technology in households with a Deaf resident.

Participants were primarily recruited through outreach to local and national disability organizations relevant to the target populations (e.g., Deaf Seniors of America, Center for the Visually Impaired Atlanta, Atlanta Post-Polio Association). Outreach efforts to relevant organizations included distributing study flyers, posting study announcements on social media pages, and hosting informational booths and sign-up sheets at conferences. In addition, participants were recruited from the Georgia Institute of Technology Human Factors and Aging Participant Registry and word of mouth referrals. For each impairment group, efforts were made to enroll a representation of both men and women in each age bracket (60-69 and 70-79). Throughout the data collection process, researchers periodically adjusted the recruitment goals for each group so that the age and gender distribution of the respective groups were similar across groups.

# 4.2. Questionnaires

Eligible participants are scheduled for an interview appointment and are asked to complete two self-report questionnaires in advance: 1) TechSAge Minimum Battery (Gonzalez, Mitzner, Sanford & Rogers, 2016) 2) ACCESS Questionnaire (See Appendix B). Combined, the two questionnaires take approximately 30 minutes to 1 hour to complete. Participants have the option to complete the questionnaires on paper or online. Participants also had the option to have a researcher administer the questionnaires by phone or videophone. Those opting to complete the

paper version are mailed the questionnaires with a pre-addressed, stamped return envelope.

Those who choose to complete the questionnaires online are emailed survey links.

#### 4.3. Interview

Interviews (1-1.5 hours) are either conducted in-person or remotely via telephone or videophone. Participants located in metro Atlanta GA or Champaign-Urbana IL have the option to complete the interview with a researcher in-person either on a university campus or at their home. At the beginning of the interview appointment, participants are reminded about the goals of the project and are asked to provide informed consent. If the interview is in-person and the participant is not blind or low vision; they are asked to sign a paper consent form. For all remote interviews or if the participant is blind or low vision, participants waived paper documentation of informed consent. Instead, these participants received an audio or video recording of the informed consent document in its entirety and the interviewer audio or video recorded their statement of consent. These audio and video consent files are stored separately from the rest of the interview audio and video files. Following informed consent, researchers check to confirm that the Minimum Battery and ACCESS questionnaires have been completed. If they have not been completed, researchers either administer the questionnaires then or set up an appointment to do so at a later date.

Immediately before the interview begins, the interviewer administers a brief supplemental questionnaire that corresponds to the participant's respective impairment group: 1) blind or low vision, 2) mobility impaired, and 3) Deaf or hard of hearing. Finally, the interviewer conducts the ACCESS interview utilizing a structured procedural guide. Interviews for mobility and vision participants are audio recorded. For Deaf participants, screen recording software is

used to record videophone interviews. Upon completion of the entire study, participants are debriefed, compensated, and thanked for their participation.

# 4.4. Transcription

Once the study is complete, audio recordings of the interview are transcribed into text files. For ASL video interviews, screen recording software is used to record the entire interview. ASL-to-English translation for both the interviewer and participant is later recorded to a separate audio file. To ensure accuracy, ASL-to-English translations of completed interviews are conducted by hearing native ASL signers who are highly familiar with the project and the questions being asked. The ASL to English translation audio files are then transcribed into text. In-person ASL interviews were video-recorded with a camcorder and translated as described.

# 5. CONCLUSION

Older adults with long-term sensory and mobility impairments are likely to experience challenges beyond those that accompany the normative aging process. There is a need for indepth research that explores not only the activity challenges experienced by this population, but also the context of the challenges and the specific components of the task that create problems and could ultimately result in disability (Harrington, Mitzner, & Rogers, 2015). The ACCESS study is the first large-scale interview study exploring user needs among older adults with long-term vision, hearing, and mobility impairments.

The ACCESS interview was strategically designed to explore difficulty across a broad range of activities, while also probing for each participant's insights on activities that are particularly challenging for them as an individual. Moreover, the interview was designed to examine participants' responses to the challenges they experience, including strategies they use to overcome them. In addition to the rich interview script, the ACCESS study features multi-

dimensional questionnaires that assess key participant characteristics (e.g., health, functional limitations, abilities) and contextual factors (e.g., housing, transportation) to provide a more holistic understanding of support needs for this understudied population.

By incorporating a number of accommodations, the ACCESS study serves as a novel method to capture the perspectives of older adults with sensory and mobility impairments. In particular, training Deaf individuals to interview the Deaf older adults, ensured their understanding of the interview questions and reflects principles from community-engaged research paradigms and ethical practices of research involving the Deaf community (Singleton, Jones & Hanumantha, 2014; Wallerstein & Duran, 2008).

A case study analysis of data from a single participant in each impairment group revealed complex challenges that are subject to a variety of factors related to the person (e.g., capabilities and limitations, financial resources, support) and their environment (e.g., housing, community infrastructure, transportation; Remillard, Mitzner, Singleton & Rogers, 2018). Findings convey the potential depth and breadth of insights about user needs among individuals aging with impairments that can be realized through this novel qualitative approach with a large, diverse sample. Detailed user needs insights can ultimately guide the development of supportive and accessible technology solutions for individuals with impairments across the lifespan.

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#### **APPENDICES**

# A. ACCESS MANUAL OF OPERATIONS (MOP)

# **Experimental Script**

Hello, <Participant Name>, how are you today? Thank you for being part of our study. We couldn't do this without your help. This study involves questionnaires and an interview that assess your experience with everyday challenges and activities. We are also interested in how you respond to those challenges.

- If in person interview (and participant is <u>not</u> Blind/low vision: To start, I would like to review a few key points from the study consent form, which you have already reviewed and signed. As a reminder, your participation is voluntarily, and you can stop at any time. Also, your results will be kept confidential and we will never identify your data by your name. Additionally, we will be audio recording <video recording for Deaf participants> this interview so that we can transcribe your responses and revisit them later. Do you have any questions before we begin?
- If remote interview or participant is Blind/low vision: To start, I would like to review the study consent form, which you have already received. <READ (OR PLAY WAIVER OF DOCUMENTATION OF CONSENT RECORDING) FOR PARTICIPANT. FOR BLIND/LOW VISION PPTS. YOU MUST AUDIO RECORD THEIR CONSENT (RECORDING OPTION CHOICE (#1 OR 2), NAME, DATE.>
  - Do you consent to be in this study?

# [CONSENT FORM MUST BE SIGNED AND SUBMITTED BEFORE INTERVIEW CAN BEGIN]

Ok. Let's move on to the questionnaires:

• If completed already: Before we get to the interview, I would like to discuss the questionnaires you completed earlier. Did you have any questions or problems completing them? <If needed, assist the participants with any difficulties they had while completing the questionnaires>

• If <u>not</u> completed in advance: <administer now, if time permits. Otherwise, set an appointment to complete over the phone]>

Before we begin the interview, I have a few questions about your [Vision/Hearing/Mobility] impairment.

<Adminster relevant supplemental questionnaire>

We are ready to begin the interview. It will take around an hour to an hour and a half\* to complete, so please feel free to take a break now to get water or use the restroom. If you need to take a break during the interview, please let me know and I will pause the recorder.

\*If the interview goes over 1.5 hours long, see the payment section on how to handle the situation.

# **ACCESS Interview Guide**

Updated 04-28-17

\*Before beginning the interview script, make sure you have a copy of both the worksheet and the laminated scale with you. For each topic, you will go between this interview script, and the worksheet and scale. Also be sure you have a video or audio recorder ready. \*

# Introduction

Thank you for you for participating in our study today. I am going to go ahead and turn on the audio (and/or video) recorder now.

#### Icebreaker

Today we're going to talk about daily living activities. To start, let's start by talking about your favorite activity.

1. Imagine you have 1 hour to do any one thing... What favorite activity or hobby would you do with this time?

For this interview, one thing we're interested in is how you may have changed the way you do things as you've gotten older. This might be for a number of reasons... maybe there's a new technology or tool you use, you've created your own way of doing it, or perhaps need more or different kinds of support.

For example, with cooking: You might use a new technology such as microwave; come up with your own way of making cooking easier, such as cooking and freezing meals to save for later; or you might not cook at all and instead someone else cooks for you or you go out to eat.

Today's interview will focus on the activities you do in everyday life. The research question we hope to answer with these interview is: What challenges do you face with everyday activities and what you do to try to manage those challenges?

# Introduction to Activity Interview

Before we get started, I'd like to go over some guidelines for this conversation.

- -First, in order to be consistent between participants, I am required to read directly from this script. I apologize if questions sound formal or repetitive. It's okay if your answers seem repetitive.
- -As a reminder, all your answers are confidential.
- -I am really interested in capturing your personal experiences and ideas. However, some of these questions might be personal. If there is anything you do not wish to discuss, we can always skip that topic. Please just let me know.
- (SKIP FOR DEAF/HH SENIORS) Please speak clearly and loudly enough for me to hear and for us to be able to transcribe the recording later.

During this interview, we will also be using a worksheet and difficulty scale. I will be reading it out loud as we go through it and noting your answers on my own copy. You do not need to fill anything out.

- If participant is blind: you do not need to give copy of worksheet and scale>
- If in person and relevant (e.g., not for completely blind participants): Give participant the worksheet and laminated difficulty scale.>

<If remote: remind participant of emailed/mailed worksheet and scale sent to them>

Here are the categories we are going to cover today:

- Activities Outside the Home
- Things You Do Around the Home
- Shopping and Finances
- Transportation
- Managing Health
- Basic Daily Activities

For each category, I'll ask you to rate different topics of activities based on how difficult they are for you to do on a 3 point scale (not all, a little, or very) difficult. Please give ratings based on the way you currently do the activity now (including any help/support you receive). I will provide some examples of activities in each topic. However, when you give a rating, please think about about the overall topic anf the things that are relevant to you. Go with your first instinct. Please hold your comments until after we finish rating each activity. Afterward, you will have a chance to discuss one topic, that's the most challenging for you, in-depth.

Let's begin with activities outside of the home.

# **Activities Outside the Home**

Let's begin with the worksheet. I will read each topic and ask you to rate how difficult those types of activities are for you \*Show participant laminated scale\*. You can rate each topic as not at all difficult, a little difficult, or very difficult. Or if the topic is not relevant to you, you can tell me that does not apply to you. Go with your first instinct for the overall category; you will have a chance to elaborate on some of these categories later. As a reminder, please hold your comments until we are finished rating each topic.

# [GO TO EXPERIMENTER WORKSHEET]

\*For each question, say "How difficult is... [read topic] and rating scale aloud to participant. Circle the participant's answers on the experimenter worksheet.\*

*If hung up on	examples, say	"Great,	we'll come	back to that.	Thinking	about the	topic <u>as c</u>	<u>a whole</u> ,	how
difficult is	for you?*								

#### Topics:

- Doing activities with a group or organization (for example, club meetings, games, classes)
- Going to entertainment events or activities (for example, movies, restaurants, sporting events)
- Participating in religious services and activities
- Visiting family and friends (for example, vacation)

Working, volunteering, or participating in other civic activities

\*Review worksheet for topics with highest difficulty ratings.\*

It looks like [insert topics with highest ratings] are the most difficult for you.

- If multiple topics are equally the most difficult ask, out the these [insert name of topics with highest ratings] is there one that is the most difficult?
  - If two topics are considered equally difficult or important, discuss both.
- If all topics were rated "not at all difficult", only ask overall category questions #1-3 We'll come back to [insert most difficult topic] in a moment to discuss further.
  - 1. How has they way you do **activities outside of the home** changed as you have gotten older, if at all?

If needed, how so/could you elaborate?

2. How has the frequency with which you do activities <u>outside</u> of the home changed as you have gotten older, if at all?

If needed, do you do these activities more or less often?

- 3. Are you satisfied with your ability to engage in **activities outside of the home**? *If needed,* how so/could you elaborate?
- 4. Thinking about **[insert topic and re-read examples]**, what aspect or part of this creates the most challenges for you?

If needed, can elaborate with words like struggle, frustrating, or concerning.

\*if a strategy is given instead of a challenge, ask "Why do you do that?"

5. How do you handle this challenge?

If needed, what do you do? So how, if at all, do you get this {task/activity} accomplished?

- 6. Do you use any sort of devices, tools, or technologies to help you with this {task/activity}?

  If not specified, what technology, device, or equipment?
- 7. Do you use any of your own methods or things you came up with to help you do that {task/activity}?

If not specified, could you tell me more about that?

8. Do you get help from anyone (for example, services, care-providers, family members) to do that {task/activity}?

If not specified, what kind of help? (for example, getting a ride)

# Things you Do Around the Home

Let's go to the next page of the worksheet. For each topic, please rank how difficult those types of activities are for you. Go with your first instinct for the overall category; you will have a chance to elaborate on some of these categories later. As a reminder, please hold your comments until we are finished rating each topic.

FOR REFERENCE ONLY—Instructions: For each category, I'll ask you to rate different topics of activities based on how difficult they are for you to do on a 3 point scale (not all, a little, or very) difficult. Please give ratings based on the way you currently do the activity now (including any help/support you receive). I will provide some examples of activities in each topic. However, when you give a rating, please think about about the overall topic any the things that are relevant to you. Go with your first instinct for the overall category; you will have a chance to elaborate on some of these categories later. Please hold your comments until after we finish rating each activity. Afterward, you will have a chance to discuss one topic, that's the most challenging for you, in-depth.

#### [GO TO EXPERIMENTER WORKSHEET]

\*For each question, say "How difficult is... [read topic] and rating scale aloud to participant. Circle the participant's answers on the experimenter worksheet.\*

*If hung up on	examples, say	"Great, ı	we'll come l	back to that.	Thinking	about the t	topic <u>as a ı</u>	vhole, i	how
difficult is	_ for you?*								

#### Topics:

- Contacting others (for example, telephone, videophone, email, texting)
- Doing hobbies at home (for example, gardening, painting, reading, watching television, playing an instrument, playing games, knitting, and other arts and crafts, learning new things)
- Housekeeping (for example, laundry, dishes, vacuuming, home organization)
- Noticing alerts (for example, doorbells, phone ringing, alarms)
- Repairing your home and maintaining it (for example, yard care, changing light bulbs, fixing leaking sinks)

It looks like [insert topics with highest ratings] are the most difficult for you.

- If multiple topics are equally the most difficult ask, out the these [insert name of topics with highest ratings] is there one that is the most difficult?
  - If two topics are considered equally difficult or important, discuss both.

<sup>\*</sup>Review worksheet for topics with highest difficulty ratings.\*

- If all topics were rated "not at all difficult", only ask overall category questions #1-3
- If something's already been covered in another category (e.g., transportation vs. getting to healthcare appointments), ask the participant to answer for the next-most difficult topic.

  We'll come back to [insert most difficult topic] in a moment to discuss further.
  - 1. How has they way you do activities <u>around</u> the home changed as you have gotten older, if at all?

If needed, how so/could you elaborate?

2. How has the frequency with which you do **activities** <u>around</u> the home changed as you have gotten older, if at all?

If needed, do you do these activities more or less often?

- 3. Are you satisfied with your ability to engage in **activities around the home**? *If needed,* how so/could you elaborate?
- 4. Thinking about **[insert topic and re-read examples]**, what aspect or part of this creates the most challenges for you?

If needed, can elaborate with words like struggle, frustrating, or concerning. \*if a strategy is given instead of a challenge, ask "Why do you do that?"

5. How do you handle this challenge?

If needed, what do you do? So how, if at all, do you get this {task/activity} accomplished?

- 6. Do you use any sort of devices, tools, or technologies to help you with this {task/activity}? *If not specified*, what technology, device, or equipment?
- 7. Do you use any of your own methods or things you came up with to help you do that {task/activity}?

If not specified, could you tell me more about that?

8. Do you get help from anyone (for example, services, care-providers, family members) to do that {task/activity}?

If not specified, what kind of help? (for example, getting a ride)

Now let's talk about...

# **Shopping and Finances**

Let's go to the next page of the worksheet. For each topic, please rank how difficult those types of activities are for you. Go with your first instinct for the overall category; you will have a chance to elaborate on some of these categories later. As a reminder, please hold your comments until we are finished rating each topic.

FOR REFERENCE ONLY—Instructions: For each category, I'll ask you to rate different topics of activities based on how difficult they are for you to do on a 3 point scale (not all, a little, or very) difficult. Please give ratings based on the way you currently do the activity now (including any help/support you receive). I will provide some examples of activities in each topic. However, when you give a rating, please think about about the overall topic any the things that are relevant to you. Go with your first instinct for

the overall category; you will have a chance to elaborate on some of these categories later. Please hold your comments until after we finish rating each activity. Afterward, you will have a chance to discuss one topic, that's the most challenging for you, in-depth.

#### [GO TO EXPERIMENTER WORKSHEET]

\*For each question, say "How difficult is... [read topic] and rating scale aloud to participant. Circle the participant's answers on the experimenter worksheet.\*

\*If hung up on examples, say "Great, we'll come back to that. Thinking about the topic <u>as a whole</u>, how difficult is \_\_\_\_\_\_ for you?\*

#### Topics:

- Applying for financial resources (for example, loans, government aid, credit cards, or other financial aid)
- Going shopping in person (groceries, clothes)
- Managing finances (for example, bills, taxes, balancing checkbook, withdrawing cash (ATM), managing savings and investments)
- Paying and signing for things (for example, using a credit card at the grocery store, paying for a cab)
- Shopping online

\*Review worksheet for topics with highest difficulty ratings.\*

It looks like [insert topics with highest ratings] are the most difficult for you.

- If multiple topics are equally the most difficult ask, out the these [insert name of topics with highest ratings] is there one that is the most difficult?
  - If two topics are considered equally difficult or important, discuss both.
  - If all topics were rated "not at all difficult", only ask overall category questions #1-3
- If something's already been covered in another category (e.g., transportation vs. getting to healthcare appointments), ask the participant to answer for the next-most difficult topic.

We'll come back to [insert most difficult topic] in a moment to discuss further.

1. How has they way you do **shopping and finance activities** changed as you have gotten older, if at all?

*If needed,* how so/could you elaborate?

2. How has the frequency with which you do **shopping and finance activities** changed as you have gotten older, if at all?

If needed, do you do these activities more or less often?

3. Are you satisfied with your ability to engage in **shopping and finance activities**? *If needed,* how so/could you elaborate?

If needed, can elaborate with words like struggle, frustrating, or concerning.
\*if a strategy is given instead of a challenge, ask "Why do you do that?"

- 5. How do you handle this challenge?
  - If needed, what do you do? So how, if at all, do you get this {task/activity} accomplished?
- 6. Do you use any sort of devices, tools, or technologies to help you with this {task/activity}? *If not specified*, what technology, device, or equipment?
- 7. Do you use any of your own methods or things you came up with to help you do that {task/activity}?

If not specified, could you tell me more about that?

8. Do you get help from anyone (for example, services, care-providers, family members) to do that {task/activity}?

If not specified, what kind of help? (for example, getting a ride)

Now let's talk about...

# **Transportation**

By transportation, we mean how you get around to places you need and want to go.

Let's go to the next page of the worksheet. For each topic, please rank how difficult those types of activities are for you. Go with your first instinct for the overall category; you will have a chance to elaborate on some of these categories later. As a reminder, please hold your comments until we are finished rating each topic.

FOR REFERENCE ONLY—Instructions: For each category, I'll ask you to rate different topics of activities based on how difficult they are for you to do on a 3 point scale (not all, a little, or very) difficult. Please give ratings based on the way you currently do the activity now (including any help/support you receive). I will provide some examples of activities in each topic. However, when you give a rating, please think about about the overall topic any the things that are relevant to you. Go with your first instinct for the overall category; you will have a chance to elaborate on some of these categories later. Please hold your comments until after we finish rating each activity. Afterward, you will have a chance to discuss one topic, that's the most challenging for you, in-depth.

#### [GO TO EXPERIMENTER WORKSHEET]

Topics:

*For each question, say "Ho	ow difficult is [ɪ	read topic] c	and rating so	cale aloud t	to participant.	Circle the
participant's answers on th	e experimenter i	worksheet.*	ŧ			

*If hung up o	on examples, say	"Great, we'll come	e back to that. T	Thinking about th	ne topic <u>as a whole</u>	, how
difficult is	for you?*					

- Arranging for transportation from a taxi, Uber, Lyft, or other service
- Driving
- Flying on an airplane (for example, navigating the airport, security, being on the plane)
- Getting a ride somewhere from a friend or family member
- Riding a train or subway
- Taking a bus
- Walking
- Wayfinding (for example, following directions, getting where you need to go)

\*Review worksheet for topics with highest difficulty ratings.\*

It looks like [insert topics with highest ratings] are the most difficult for you.

- If multiple topics are equally the most difficult ask, out the these [insert name of topics with highest ratings] is there one that is the most difficult?
  - If two topics are considered equally difficult or important, discuss both.
  - If all topics were rated "not at all difficult", only ask overall category questions #1-3
- If something's already been covered in another category (e.g., transportation vs. getting to healthcare appointments), ask the participant to answer for the next-most difficult topic.

We'll come back to [insert most difficult topic] in a moment to discuss further.

1. How has they way you do **your transportation/getting around** changed as you have gotten older, if at all?

If needed, how so/could you elaborate?

2. How has the frequency with which you do **your transportation/getting around** changed as you have gotten older, if at all?

If needed, do you do these activities more or less often?

- 3. Are you satisfied with your ability to engage in **your transportation/getting around**? *If needed,* how so/could you elaborate?
- 4. Thinking about [insert topic and re-read examples], what aspect or part of this creates the most challenges for you?

If needed, can elaborate with words like struggle, frustrating, or concerning.

\*if a strategy is given instead of a challenge, ask "Why do you do that?"

5. How do you handle this challenge?

If needed, what do you do? So how, if at all, do you get this {task/activity} accomplished?

- 6. Do you use any sort of devices, tools, or technologies to help you with this {task/activity}? If not specified, what technology, device, or equipment?
- 7. Do you use any of your own methods or things you came up with to help you do that {task/activity}?

If not specified, could you tell me more about that?

8. Do you get help from anyone (for example, services, care-providers, family members) to do that {task/activity}?

If not specified, what kind of help? (for example, getting a ride)

Now let's talk about...

## **Managing Health**

Let's go to the next page of the worksheet. For each topic, please rank how difficult those types of activities are for you. Go with your first instinct for the overall category; you will have a chance to elaborate on some of these categories later. As a reminder, please hold your comments until we are finished rating each topic.

FOR REFERENCE ONLY—Instructions: For each category, I'll ask you to rate different topics of activities based on how difficult they are for you to do on a 3 point scale (not all, a little, or very) difficult. Please give ratings based on the way you currently do the activity now (including any help/support you receive). I will provide some examples of activities in each topic. However, when you give a rating, please think about about the overall topic any the things that are relevant to you. Go with your first instinct for the overall category; you will have a chance to elaborate on some of these categories later. Please hold your comments until after we finish rating each activity. Afterward, you will have a chance to discuss one topic, that's the most challenging for you, in-depth.

## [GO TO EXPERIMENTER WORKSHEET]

\*For each question, say "How difficult is... [read topic] and rating scale aloud to participant. Circle the participant's answers on the experimenter worksheet.\*

*If hung up on	examples, say	"Great, w	ve'll come b	ack to that.	Thinking	about the	topic <u>as a</u>	whole,	how
difficult is	for you?*								

#### Here are the topics:

- Accessing health information access (for example, finding health information online, contacting Medicare/insurance and advocacy groups for health resources)
- Caring for others (for example, a sick family member)
- Exercising (for example, in general or fitness classes, gyms, sports)
- Getting help in case of emergency (for example, calling 911)
- Going to healthcare provider appointments (for example, making, remembering or getting to the appointment)

- Managing your diet and nutrition (for example, figuring out what to eat, tracking calories, keeping hydrated, preparing meals)
- Managing medications (for example, getting prescriptions filled, remembering to take them)
- Monitoring health (for example, blood pressure monitor, blood-glucose readers, weight, activity tracking)

\*Review worksheet for topics with highest difficulty ratings.\*

It looks like [insert topics with highest ratings] are the most difficult for you.

- If multiple topics are equally the most difficult ask, out the these [insert name of topics with highest ratings] is there one that is the most difficult?
  - If two topics are considered equally difficult or important, discuss both.
  - If all topics were rated "not at all difficult", only ask overall category questions #1-3
- If something's already been covered in another category (e.g., transportation vs. getting to healthcare appointments), ask the participant to answer for the next-most difficult topic.

We'll come back to [insert most difficult topic] in a moment to discuss further.

- 1. How has they way you **manage your health** changed as you have gotten older, if at all? *If needed*, how so/could you elaborate?
- 2. How has the frequency with which you **manage your health** changed as you have gotten older, if at all?

If needed, do you do these activities more or less often?

- 3. Are you satisfied with your ability to engage in **managing your health**? *If needed,* how so/could you elaborate?
- 4. Thinking about **[insert topic and re-read examples]**, what aspect or part of this creates the most challenges for you?

If needed, can elaborate with words like struggle, frustrating, or concerning. \*if a strategy is given instead of a challenge, ask "Why do you do that?"

5. How do you handle this challenge?

*If needed*, what do you do? So how, if at all, do you get this {task/activity} accomplished?

- 6. Do you use any sort of devices, tools, or technologies to help you with this {task/activity}?
  If not specified, what technology, device, or equipment?
- 7. Do you use any of your own methods or things you came up with to help you do that {task/activity}?

If not specified, could you tell me more about that?

8. Do you get help from anyone (for example, services, care-providers, family members) to do that {task/activity}?

If not specified, what kind of help? (for example, getting a ride)

Now let's talk about...

## **Basic Daily Activities**

Now let's talk about basic daily activities. As a reminder, some questions may be personal. If you do not feel comfortable answering a question, please let me know and we will skip to the next one.

Let's go to the next page of the worksheet. For each topic, please rank how difficult those types of activities are for you. Go with your first instinct for the overall category; you will have a chance to elaborate on some of these categories later. As a reminder, please hold your comments until we are finished rating each topic.

FOR REFERENCE ONLY—Instructions: For each category, I'll ask you to rate different topics of activities based on how difficult they are for you to do on a 3 point scale (not all, a little, or very) difficult. Please give ratings based on the way you currently do the activity now (including any help/support you receive). I will provide some examples of activities in each topic. However, when you give a rating, please think about about the overall topic any the things that are relevant to you. Go with your first instinct for the overall category; you will have a chance to elaborate on some of these categories later. Please hold your comments until after we finish rating each activity. Afterward, you will have a chance to discuss one topic, that's the most challenging for you, in-depth.

#### [GO TO EXPERIMENTER WORKSHEET]

\*For each question, say "How difficult is... [read topic] and rating scale aloud to participant. Circle the participant's answers on the experimenter worksheet.\*

\*If hung up on examples, say "Great, we'll come back to that. Thinking about the topic <u>as a whole</u>, how difficult is \_\_\_\_\_ for you?\*

#### Here are the topics:

- Bathing, showering, or grooming (for example, shaving, make-up, brushing teeth)
- Dressing
- Eating or feeding yourself
- Moving around in your home
- Toileting
- Transferring (getting around your home, transferring in and out of bed, on and off the toilet, or in and out of the shower)

\*Review worksheet for topics with highest difficulty ratings.\*

It looks like [insert topics with highest ratings] are the most difficult for you.

- If multiple topics are equally the most difficult ask, out the these [insert name of topics with highest ratings] is there one that is the most difficult?
  - If two topics are considered equally difficult or important, discuss both.
  - If all topics were rated "not at all difficult", only ask overall category questions #1-3
  - If something's already been covered in another category (e.g., transportation vs. getting

to healthcare appointments), ask the participant to answer for the next-most difficult topic.

We'll come back to [insert most difficult topic] in a moment to discuss further.

- 1. How has they way you do **basic daily activities** changed as you have gotten older, if at all? *If needed*, how so/could you elaborate?
- 2. How has the frequency with which you do **basic daily activities** changed as you have gotten older, if at all?

If needed, do you do these activities more or less often?

3. Are you satisfied with your ability to engage in basic daily activities?

*If needed,* how so/could you elaborate?

4. Thinking about **[insert topic and re-read examples]**, what aspect or part of this creates the most challenges for you?

If needed, can elaborate with words like struggle, frustrating, or concerning.

\*if a strategy is given instead of a challenge, ask "Why do you do that?"

5. How do you handle this challenge?

If needed, what do you do? So how, if at all, do you get this {task/activity} accomplished?

- 6. Do you use any sort of devices, tools, or technologies to help you with this {task/activity}? *If not specified*, what technology, device, or equipment?
- 7. Do you use any of your own methods or things you came up with to help you do that {task/activity}?

If not specified, could you tell me more about that?

8. Do you get help from anyone (for example, services, care-providers, family members) to do that {task/activity}?

If not specified, what kind of help? (for example, getting a ride)

## **Activity Wrap Up**

Okay, we're just about finished with this interview. I'd like you to think about <u>everything</u> we've discussed today or anything else that you do.

FOR REFERENCE ONLY—Instructions: If participants qualified for **dual conditions**, ask question C and D for **both i**mpairment.

- A. What has been the most challenging activity for you as you have gotten older?
  - a. How does that make you feel?
- B. What activity do you feel that you have dealt with most successfully?
  - a. How does that make you feel?
- C. How do you think that \*(select appropriate one)
  - -being Deaf/Hard of Hearing OR
  - -having a vision impairment OR
  - -having a mobility impairment

for a long period of time has helped you to get stronger to face challenges as you get older?

D. What advice would you give to other (Deaf people, OR people with vision impairment OR people with mobility impairment) as they age for dealing with some of these challenges?

Thanks! The interview is finished, so I will turn off the recorder now.

## **Closing Script**

Thank you, <Participant Name> for your time! We could not have done this without your help. If you have any questions for us, please let us know, and we are finished with the study! Now we will debrief you on the research study you just participated in.

#### Debriefing

- If in-person: <Give a copy of the debriefing form to the participant>Explain the purpose and goals for the experiment, answer any questions they may have, and thank them for their time.
- If the interview is occurring remotely: <a physical copy is not needed, but you should still read the debriefing form to the participants> Explain the purpose and goals for the experiment, answer any questions they may have, and thank them for their time.>
- Debrief Summary: Little is known about the aging challenges people with sensory and mobility impairments experience. In this study we are exploring the challenges you experience with every day activities and how you manage these challenges. We covered many different topics rated how difficult they are for you to do, and we focused in depth on the most challenging activity for each category. We hope that findings from this study will help increase awareness of these challenges and create interventions that can help other people facing similar challenges. Please remember that all of your personal information and responses are confidential. If you have any questions, feel free to contact us. Our contact information is on the debriefing form, as well as more detailed information about this study and what we did today. Again, thank you for your help today! We are actively recruit for this study and are looking for adults:
  - o Be between the ages of 60-79
  - Self-identify with one of the following:
    - Blind/low vision: having serious difficulty seeing even when wearing glasses
    - Deaf/hard of hearing: using American Sign Language (ASL) as primary language for communication
    - Mobility impaired: using a mobility aid (i.e., cane, crutches, wheelchair, walker, or scooter) and having serious difficulty walking or climbing stairs (or unable to walk or climb stairs)
  - o Have had the vision, hearing or mobility impairment prior to age 50
  - o Be fluent in English or American Sign Language (ASL)
  - Live in the United States

Please pass our information along to anyone who might be interested and might qualify for our study. Interested participants should contact Elena Gonzalez at 404-385-2564 or via email at <a href="mailto:elena.gonzalez@design.gatech.edu">elena.gonzalez@design.gatech.edu</a>. Do you know of any organizations or community groups we should reach out to for access to these populations?

#### Payment [If ALL portions of the interview and questionnaires have been completed]

- If in person, have the participant sign for the check (on multi-participant log) and provide them a check.
  - For blind/low vision: offer option to have it mailed if they are uncomfortable signing.
- If the interview is occurring remotely, confirm the participant's mailing address, and tell them to look for it in the mail. Also, tell participants to complete the check signature sheet that they will receive in the mail and to please mail that in the pre-addressed and pre-paid envelope back to you. Then, mail out the check. Materials needed for this include: The check, cover letter, pre-addressed and pre-paid envelope, & Signature sheet

#### Payment [If all portions of the interview and questionnaires have NOT been completed]

- Say the following: 1) We will mail the check once all portions of the interview and
  questionnaires have been completed. 2) We may follow up with a phone call to administer
  questionnaires or ask follow-up questions.
- Confirm the participant's mailing address, and tell them to look for it in the mail. Also, tell
  participants to complete the check signature sheet that they will receive in the mail and to
  please mail that in the pre-addressed and pre-paid envelope back to you. Then, mail out the
  check. Materials needed for this include: The check, cover letter, pre-addressed and pre-paid
  envelope, & Signature sheet

### Payment [If the participant goes longer than the hour and a half for the interview]

- If it goes up to an hour over, ask if they are willing to continue.
- If it goes more than an hour over, we'll compensate \$12 for additional hour to finish.
  - If you need to finish the remainder of the interview at a later time, indicate this on their checklist

#### **B. SCREENING SCRIPT**

## **ACCESS Phone Screening Script**

Enter responses into ACCESS Scheduling and Tracking excel sheet

Hello my name is [name] and I'm calling from the Human Factors & Aging Lab at Georgia Tech. Thank you for expressing interest in our study. This is a one-time interview study that explores the challenges older adults with long-term mobility and sensory impairments have with everyday activities. We are interested in understanding what the challenges are and how they manage these challenges as they age. This study is a joint effort between two universities including Georgia Tech and Illinois. The interview can be completed in person if located in Metro Atlanta GA or Champaign-Urbana IL (either at Georgia Tech or your home) or remotely (through phone or video call). Participants will be compensated \$30 after they have completed both the questionnaires and the interview. Would you be interested in participating?

- If no, Thank you for your time.
  - Add to participant list that they are not interested in the study in the comment column.
- If yes, Do you have 10-15 minutes to go through some questions?
  - o If yes, continue with script.
  - o *If no*, Is there a time we could schedule for me to call?
    - Add information to participant list in the comment column.

First, let me start by getting your contact information.

### **Contact Information**

- What is your first and last name?
- Phone number?
- Home Address? [Read back address to confirm it is correct for check writing purposes]
  - If concerned about giving address, if you qualify, we will need your address to send the study information and questionnaires to you. You can provide this later if you prefer
- Do you have an email address? If yes, please spell it for me. [Read back email address to confirm it is correct.]
- How did you learn about this study?
- We maintain a list of people interested in participating in research projects. Would you like to be added?
  - o *If yes, enter Y.* Ok great! Someone will contact you at a later time to get the rest of your information.
  - o *If no, enter N*. Okay, no problem!

#### **Screening**

Before I start, I want to let you know there are no right or wrong answers, and all the information that you are giving me are kept confidential. Some of the questions are Yes/No and others are short answers.

## Are you ready to start?

Now I am going to ask you a few questions. Enter responses in excel spreadsheet.

- What is your date of birth?
- What is your primary language for communicating?

Now we are going to ask you a few questions about different abilities and limitations. Regarding your vision:

- Do you identify as being Blind?
- Do you identify as being Low Vision? By low vision we mean individuals who have trouble seeing, even when wearing glasses or contact lenses. Low vision refers to a loss of vision that may be severe enough to hinder an individual's ability to complete daily activities such as reading, cooking, or walking outside safely, while still retaining some degree of useable vision.
  - o If no to blind OR low vision: move on to hearing.
  - o If yes to blind OR low vision,
    - Could you describe the nature of your vision impairment? Write down response (e.g., totally blind, legally blind, one or both eyes)
    - At what age did your vision impairment begin?
      - If before age 50, How did you become blind or low vision?
      - If after age 50 (including 50), move on.

## Regarding your hearing:

- Do you identify as being Deaf or hard of hearing?
  - o *If no, move onto mobility.*
  - o If yes,
    - Do you use ASL as your primary language?
      - *If no, move onto mobility.*
      - *If yes:* Ok. Thank you.
    - At what age did you become deaf or hard of hearing?
      - If after age 50 (including 50), move on.
      - If before age 50, How did you become deaf or hard of hearing?

## Regarding your mobility:

- Do you identify as having a mobility impairment?
  - o If no, move on.
  - o If unsure, continue with questions below.
  - o If yes,
    - Do you use a mobility aid to help you move from place to place? (i.e., cane, crutches, wheelchair, walker, scooter)
      - If yes, what mobility aid(s) do you use?
        - Write response in spreadsheet and move onto next question.
      - If no: move on to next question (must use mobility aid OR have serious difficulty walking or climbing stairs).

- Do you have serious difficulty walking or climbing stairs? (note-this would also include anyone who is unable to walk or climb stairs)
  - *If yes*: move on to next question.
  - If no: to qualify, ppt. must use mobility aid OR have serious difficulty walking or climbing stairs
    - o *If no to both, end mobility questions*
    - If yes to either: move onto next question.
- At what age did your mobility impairment begin?
  - If after age 50 (including 50), end mobility questions.
  - If before age 50, How did you become mobility impaired?

\*Note: to be eligible, ppt must:

- identify as having a mobility impairment
- -use a mobility aid OR have serious difficulty (or inability) walking or climbing stairs
- have had mobility impairment prior to age 50.

#### **MULTIPLE IMPAIRMENTS:**

If more than one impairment started before the age of 50,

- Could you please tell us which of the impairments you had before the age of 50 creates the most challenges for you?
  - Write down response and put them in the group that is their most challenging impairment.

If Deaf AND vision impaired (screening Q's for phone or email):

- "The interview can be administered in English or American Sign Language:
  - Can you see well enough to do the interview in ASL through a video call?
  - o (only if local-within 1 hour of Atlanta or Champaign) Can you see well enough do the interview in ASL in person?"
    - If no to either: unfortunately, you will not be able to participate in this study. [Offer opportunity to join registry]. Thank you for your interest.
    - *If yes, notify Deaf interviewing team.*

Once you have completed the screening:

Rate your agreement with following statements and enter into the excel sheet:

1) The participant understood the questions without needing them repeated.

(1=agree 2=somewhat agree 3=disagree)

2) The participant gave responses to the questions that made sense/were logical.

(1=agree 2= somewhat agree 3=disagree)

3) The participant has a clear understanding of what the study entails did not seem confused.

(1=agree 2= somewhat agree 3=disagree)

\*Note: If you mark any 3's for a participant, consult with the research team to share your concerns and to determine whether or not that individual is a good candidate for the study.

### **CLOSING SCRIPT**

### Unsure if eligible?

I really appreciate you taking the time to answer my questions and thank you for holding. My job on the project is to gather information from potential participants. I will need to check with my supervisor to see if you qualify". When would be a good time to call you back? **SCHEDULE TIME TO CALL BACK & CHECK WITH RESEARCH TEAM ABOUT ELIGIBILITY.** 

## Ineligible participants

I really appreciate you taking the time to answer my questions and thank you for holding. For this study, unfortunately are not eligible. With your permission, however, we would like to retain your name in our registry should there be a program in the future that you are eligible for.

## Eligible participants

I really appreciate you taking the time to answer my questions and thank you for holding. You are eligible for this study.

- Do you wish you participate?
  - o If "No", Thank-you so much for your interest and time, please call us back if you change your mind.
  - o If "Yes, continue with interview scheduling.

## Scheduling the Interview

- The interview will take about 1-1.5 hours to complete. We want to make the interview convenient for you, so there are a few ways to participate. If you are located in Metro Atlanta GA or Champaign-Urbana IL 1) You can do the interview in person with a researcher on Georgia Tech's campus or 2) Researchers can come to your home to do the interview. If you are not located in Metro Atlanta GA or Champaign-Urbana IL 3) You can do the interview over the phone. What would you prefer?
- o 1) In-person interview at Georgia Tech or Illinois
  - If preferred, discuss availability of ppt. and researchers and SCHEDULE
     APPT (min of 2 weeks out so they have time to complete the q'aires)
  - Thank you. I will send you directions to the lab (and a parking pass?) with your study materials.
- o 2) Home visit
  - If preferred, discuss availability of ppt. and researchers and **SCHEDULE APPT.** (min of 2 weeks out so they have time to complete the q'aires)
  - Thank you. Are there any special instructions for visiting your home (e.g., gates, parking instructions)?
- o 3) Phone interview
  - If preferred, discuss availability of ppt. and researchers and SCHEDULE APPT. (min of 2 weeks out so they have time to complete the q'aires)
  - What is the best number to reach you at that time?
  - As a reminder, the call will be audio recorded. Please try to be somewhere quiet without background noise and interruptions.

#### Questionnaires

- Lastly, let's figure out how you would like to complete the pre-interview questionnaires. You can choose to complete the questionnaires using pen and paper OR you can do it online. If you want the paper copy, we will mail it to you. If you prefer to complete the questionnaire online, we can email you the survey links. If you are unable to do the questionnaires yourself and need help, we can schedule a time for one of our research assistants to ask you the questions over the phone. What do you prefer?
  - o <u>If ppt. wants to be mailed the paper copy:</u> Okay. I will send the packet with the study consent form and questionnaires to your home address. **SEND PACKET** 
    - 1) Cover letter (remote or in-person)
    - 2) Consent (remote-waiver or in person-consent)
    - *3) Minimum Battery*
    - 4) ACCESS questionnaire
    - 5) large self-addressed, stamped return envelope
    - 6) Participant Worksheet
    - 7) Difficulty scale
  - o <u>If ppt. wants to be emailed the survey links:</u> Okay. I will send you an email shortly with your study ID and link. When you click the link, it will take you to a page on our website where you can all the study materials and the questionnaire surveys to complete. If you do not receive the email or have any issues completing the questionnaires, please email or call us for help. **SEND EMAIL WITH ACCESS LANDING PAGE LINK & SURVEY ID**
  - o <u>If ppt. is unable to do the questionnaires:</u> Ok. We can schedule a separate time for one of our research assistants to ask you the questions over the phone. Would you like to schedule that now?
  - We encourage you to complete the questionnaires before the interview.

### Confirm interview & mailing:

• Thank you. I have your interview scheduled for [insert date and time] at [insert location: lab/home/phone call]. Let me re-read your mailing address to confirm we have the right address [For ALL participants, not just home]. The person leading your interview will call you the day before to confirm your appointment. Please call or email if you have any questions, need to re-schedule, or do not receive your study materials (via mail or email). END SCRIPT

## C. ACCESS QUESTIONNAIRE

This questionnaire will ask you to provide information about your everyday life. If there is a question that does not apply to you or that you do not wish to answer, please leave it blank and go on to the next question.

## **Life Space Assessment**

The following questions will ask how often you go to different areas in your home and community and what you might use to get you there.

1.	D	o you currently use any of the	e following aids? (Check all	that apply)
a.		Cane or walking stick		
b.		Walker		
c.		Wheelchair		
d.		Special "rising-seat-chair"/"	lift-chair"	
e.		Ramp		
f.		Crutch or crutches		
g.		Brace		
h.		Artificial limb		
i.		Runabout, Scooter		
j.		ceil Bar on rails in bathroom, tul	b, or shower	
k.		Bath chair		
1.		Roll-in shower		
m.		Bedside commode or toilet/	raised toilet seat	
n.		Bed Pan		
o.		Hospital bed		
p.		Ventilator		
q.		Oxygen/special breathing ed	quipment (inhalers, atomize	ers, nebulizers, etc.)
r.		None		
Le				
		. During the past four weeks,	•	ms of your home
	be	esides the room where you sle	ep?	
		Yes	No	

12	2. How did you get to	places or	ıtside your	neighborhood	d, but wi	thin your	
	town?	• 1	. 1		1	0	
	a. Did you use aids or special equipment to get there?						
	Yes	3		No	Don't l	know or do not	
					wis	h to answer	
b. Did you need help from another person to get there?							
	Yes	S		No		know or do not	
					wis	h to answer	
Level 5 13. During the past four weeks, have you been to places outside your town?							
			L				
	Yes		N	Го			
14	. If yes, how often h	ave you be	een to place	es outside you	ır town?		
	Less than once per week	1-3 times	s per week	4-6 times pe	r week	Daily	
15	. How did you get to a. Did yo	-	_	own? equipment to	get ther	<u>e</u> 9	
		<u>a ase aras</u>	or special		get ther		
	Yes	<u> </u>		No	Don't l	know or do not	
					wis	h to answer	
	b. Did yo	u need he	lp from and	ther person to	o get the	ere?	
	Yes	S		No	Don't l	know or do not	
					wis	h to answer	

## **Technology Adoption Style**

For the following questions, please think about when a new technology goes on the market. For each question you will rate the extent of your agreement on the following scale: strongly disagree, disagree, neither agree nor disagree, agree, or strongly agree. Circle one number for each item.

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
1. When approached with a new technology, I tend to be the last of my peers (friends) to begin using it.	1	2	3	4	5
2. I have to be one of the first people to purchase a new technology.	1	2	3	4	5
3. When a new technology comes out, I am afraid to use it.	1	2	3	4	5
4. I introduce people to new technologies.	1	2	3	4	5

## **Quality of Life**

The following questions are about your quality of life. You will rate different aspects of your life using one of four words: poor, fair, good, or excellent. Circle one number for each item.

one number for each item.				
	Poor	Fair	Good	Excellent
1. How do you feel about your physical	1	2	3	4
health?				'
2. How do you feel about your energy	1	2	3	4
level?	1	2	3	4
3. How has your mood been lately?	1	2	3	4
4. How do you feel about your living	1	2	3	4
situation?	1	<u> </u>	3	4
5. How do you feel about your	1	2	3	4
memory?	1	2	3	4
6. How do you feel about your family				
and your relationship with family	1	2	3	4
members?				
7. How do you feel about your	1	2	3	4
marriage or other close relationship(s)?	1	<u> </u>	<u> </u>	4
8. How would you describe your	1	2	3	4
current relationship with your friends?	1	<u> </u>	3	4
9. How do you feel about yourself as a	1	2	3	4
whole?	1			<b>T</b>
10. How do you feel about your ability				
to do things like chores around the	1	2	3	4
house or other things you need to do?				
11. How do you feel about your ability	1	2	3	4
to do things for fun that you enjoy?	1	<u> </u>	J	7
12. How do you feel about your current				
situation with money, financial	1	2	3	4
situation?				
13. How would you describe your life	1	2	3	4
as a whole?	1	<u> </u>	J	7

# **Transportation Access**

The next few questions will ask about your use and access to transportation options.

. Which of the following apply to you? (Check all that apply)
a. Have driven a car before
b. Have a valid driver's license and are able to drive
c. Have driven a car in the past year
d. Drive a car regularly
e. Drive as a primary mode of transport
f.  Others depend on you to drive them
g.   Stopped driving more than one year ago
h. Stopped driving within the past year
i. None of the above
2. Which of the following types of transportation do you have access to? Check all that apply)
a.   I do not have access to transportation
b. A car you can drive
c. Someone who can drive you in a car
d. Public transit <u>bus</u>
e. Public transit <u>train</u>
f. Mobility bus/public transportation for those with disabilities
g. Complimentary shuttle
h. Taxi service
i.  Other (please specify)

3. How often do you use each of the following methods of transportation, based on the last few months? (Check one for each row)

	Daily	Weekly	Monthly	Less than once a month	Never
a. Walk					
b. Use a wheelchair or scooter					
c. Drive a car					
d. Ride in a car that someone else drives					
e. Public transit bus					
f. Public transit train					
g. Take a mobility bus/public transportatio n for those with disabilities					
h. Take a complimenta ry shuttle					
i. Take a taxi					

## **Formal Care and Services**

Now we have some questions about services that you may have received from an agency or from someone paid privately to provide this help.

1.	In the past month, did you have a formal caregiver who helped with shopping cleaning, laundry and preparing meals?					
	cleaning, laundr	y and preparing	meals?			
	No	Yes	Unknov	vn	Do not	wish to
					ans	swer
	b. How often?					
	Daily	Weekly	Monthly	Less t	han once	Never
				a n	nonth	
2.	In the past mont with personal ca	<u> </u>	_			-
	No	Yes	Unknov	vn		wish to
					ans	swer
	b. How often?					
	Daily	Weekly	Monthly	Less t	han once	Never
				a n	nonth	
3.	In the past mont meals delivered	• •		w cost	meals or	have cooked
	No	Yes	Unknov	vn	Do not	wish to
						swer
			1			
1	o. How often?					
				[		
	Daily	Weekly	Monthly	Less t	han once	Never
				a n	nonth	

4.	In the past month, did you have a visiting nurse come to check on medications						
	blood pressure, or other medical needs?						
	No	Yes	Unknow	n Do not	t wish to		
				ans	swer		
	b. How often?						
	Daily	Weekly	Monthly	Less than once	Never		
				a month			

# D. VISION SUPPLEMENTAL QUESTIONNAIRE

1.	What is your date of birth?			
2.	What was the primary cause of your	vision impairment? Please s	select one and describe.	
	Condition or Illness	Accident or Event	☐ Unknown	
Please	describe:			
	2a. At what age did your vision impa	airment begin?		
3.	Which type(s) of vision impairment	do you have? Select all that	t apply.	
	Completely Blind *if checked, en	nd here.		
	☐ Blurred Vision			
	Color Blindness			
	Extreme Light Sensitivity			
	Generalized Haze			
	Loss of Central Vision			
	Loss of Peripheral (Side) Vision			
	Night Blindness			
	Other (please describe):			
4.	What is your visual acuity?			

Ш	$  \geq 20/25$ visual acuity	
	20/30 to 20/60 visual acuity	
	20/70 to 20/160 visual acuity	
	20/200 to 20/400 visual acuity OR 10 to 20 degrees of visual field	
	20/500 to 20/1,000 visual acuity OR 5 to 10 degrees of visual field	
	$\leq 20/1,000$ visual acuity OR $\leq 5$ degrees of visual field	
	Does not know	
5. '	Think about your better eye when correction, how well can you read? Check one.  Can read small print	
5. '	Can read small print	
5. '	¬	
5. '	Can read small print Can read regular print but cannot read small print	
5.	Can read small print Can read regular print but cannot read small print Near-normal with appropriate reading aids or use of low power magnifiers	
5.	Can read small print Can read regular print but cannot read small print Near-normal with appropriate reading aids or use of low power magnifiers Slower than normal with reading aids or use of high power magnifiers	

Other

# E. DEAF AND HARD OF HEARING SUPPLEMENTAL QUESTIONNAIRE

1.	1. What is your date of birth?								
2.	What was the primar	y cause of your deafness or le	oss of hearing? Please sel	ect one and describe					
	Condition or Illne	ss Acciden	t or Event Unk	nown					
Plea	Please describe:								
3.	<ul><li>2a. At what age did you become deaf or hard of hearing?</li><li>3. Which type of hearing loss do you have? Please select one for each question.</li></ul>								
a. l	Bilateral OR	☐ Bilateral: hearing loss in	both ears	Unilateral: hea	ring loss is normal in one ear				
ı	Unilateral?			but there is hearing	g loss in the other				
b. S	Symmetrical OR	Symmetrical: degree and	d configuration of	Asymmetrical: degree and configuration of					
A	Asymmetrical?	hearing loss are the same in	each ear	hearing loss are di	fferent in each ear				
c. l	Progressive OR	Progressive: hearing	Sudden: hearing loss	that happens	□ N/A from birth				
\$	Sudden?	loss that becomes worse	quickly; requires immed	iate medical					
		over time	attention to determine its	s cause and					
			treatment						

d. Fluctuating OR	☐ Fluctuating: hearing loss that changes over	Stable: hearing loss does not change over
Stable?	time—sometimes getting better, sometimes getting	time and remains the same
	worse	

4. What is your hearing loss range in decibels?

Left Ear	Right Ear
-10 to 15	-10 to 15
16 to 25	16 to 25
26 to 40	26 to 40
41 to 55	41 to 55
56 to 70	56 to 70
71 to 90	71 to 90
91+	91+
Do not know	Do not know

# F. MOBILITY SUPPLEMENTAL QUESTIONNAIRE

1.	What is your date of birth?			
2.	What was the primary cause of you	ır mobility impairment? Plea	se select one and describe.	
	☐ Condition or Illness	☐ Accident or Event	□ Unknown	
Plea	se describe:			
	2a. At what age did your mobility is	impairment begin?		
3.	Which type(s) of mobility impairm	ent do you have? Select all the	hat apply.	
	$\square$ Arm Strength (Upper limbs are	not strong enough to use a w	alker, crutches or a cane)	
	☐ Balance (Loss of ability to ambi	• •	are going to fall)	
	☐ Endurance (Loss of energy to co ☐ Leg Strength (Lower limbs are r		2)	
	☐ Motor Control (Difficulty movin			
	☐ Pain (Discomfort limits ability t	,		
	☐ Range of Motion (Difficulty mo	•		
	☐ Sensation (Loss of feeling in a b	• •		
	Other			
4.	What is your degree of mobility lo	ss with walking?		-
	I can walk and run			-
	I can walk but not run			

I can walk with cane
I can walk with a walker
I can move using a wheelchair
I can only move if someone else assists with the wheelchair

#### G. ACCESS INTERVIEWER WORKSHEET

This worksheet should be administered with the ACCESS Interview Script (in MOP). Provide participant with copy of difficulty rating scale and ACCESS Participant Worksheet. For each of the 6 categories of topics, you will have the participant rate the difficulty of several topics when those prompts occur in the interview script (i.e., you will be switching between the worksheet and the interview script during the interview.) You will read each topic out loud (or sign for Deaf participants). The participant may reference the copy of the scale, and you should read the answer choices out loud.

The participant will rate these topics out loud during the interview you will record their answers on this worksheet. To record the answer, you should circle the difficulty rating for each topic on the worksheet. Instruct participants to give ratings based on the way they do the activity now (including any help/support they receive). The rating should focus on the topic as a whole, not just a specific activity. There is a comments section below each topic. Write down any specific activities within the topic the participant discusses in detail as being difficult. If participant says topic "does not apply" ask them why and include reason in comments.

You will then use the worksheet to select the most difficult topic for the participant for each category. On the worksheet, you should mark the most difficult topic by circling the topic itself. If the participant cannot choose one most difficult topic, the participant may choose two (in which case you should circle both topics on the worksheet). If they say nothing is difficult, ask one more time to see if they think of anything; if they still do not identify a most challenging activity, move onto the next category.

\*Remember—this interview script was designed to guide the discussion and get participants thinking about challenges. High priority is having them talk about challenges related to their impairment (not the ratings).

# **Activities Outside the Home**

Topic	How Difficult is			
Doing activities with a group or organization (for example, club meetings, games, classes)  Comments:	Not at all	A little	Very	Does Not Apply
Going to entertainment events or activities (for example, movies, restaurants, sporting events)  Comments:	Not at all	A little	Very	Does Not Apply
3. Participating in religious services and activities <i>Comments:</i>	Not at all	A little	Very	Does Not Apply
4. Visiting family and friends (for example, vacation)  Comments:	Not at all	A little	Very	Does Not Apply
5. Working, volunteering, or participating in other civic activities  Comments:	Not at all	A little	Very	Does Not Apply

# Things You Do Around the Home

Торіс		How Diff	icult is	
Contacting others (for example, using the phone, VideoPhone, email, texting)  Comments:	Not at all	A little	Very	Does Not Apply
2. Doing hobbies at home (for example, gardening, painting, reading, watching television, playing an instrument, playing games, knitting, and other arts and crafts, learning new things)  Comments:	Not at all	A little	Very	Does Not Apply
Housekeeping (for example, laundry, dishes, vacuuming, home organization)     Comments:	Not at all	A little	Very	Does Not Apply
4. Noticing alerts (for example, door bells, phones ringing, alarms)  Comments:	Not at all	A little	Very	Does Not Apply
5. Repairing your home and maintaining it (for example, yard care, changing light bulbs, fixing leaking sinks)  Comments:	Not at all	A little	Very	Does Not Apply

# **Shopping and Finances**

Topic	How Difficult is			
Applying for financial resources (for example, loans, government aid, credit cards, or other aid)     Comments:	Not at all	A little	Very	Does Not Apply
2. Going shopping in person (for example, groceries, clothes)  Comments:	Not at all	A little	Very	Does Not Apply
3. Managing finances (e.g., paying bills, paying taxes, balancing checkbook, withdrawing cash (ATM), managing savings and investments)  Comments:	Not at all	A little	Very	Does Not Apply
4. Paying and signing for things (e.g., using a credit card at the grocery store, paying for a cab)  Comments:	Not at all	A little	Very	Does Not Apply
5. Shopping online Comments:	Not at all	A little	Very	Does Not Apply

# Transportation

Торіс	How Difficult is			
1. Arranging for transportation from a taxi, Uber, Lyft, or other service <i>Comments:</i>	Not at all	A little	Very	Does Not Apply
2. Driving Comments:	Not at all	A little	Very	Does Not Apply
3. Flying on an airplane (for example, navigating the airport, security, being on the plane)  Comments:	Not at all	A little	Very	Does Not Apply
4. Getting a ride somewhere from a friend or family member <i>Comments:</i>	Not at all	A little	Very	Does Not Apply
5. Riding a train or subway Comments:	Not at all	A little	Very	Does Not Apply
6. Taking a bus Comments:	Not at all	A little	Very	Does Not Apply
7. Walking Comments:	Not at all	A little	Very	Does Not Apply
8. Wayfinding (for example, following directions, getting where you need to go)  Comments:	Not at all	A little	Very	Does Not Apply

**Managing Health** 

Topic	How Difficult is			
Accessing health information (for example, finding health information online, contacting Medicare/insurance and advocacy groups for health resources)  Comments:	Not at all	A little	Very	Does Not Apply
2. Caring for others (for example, a sick family member)  Comments:	Not at all	A little	Very	Does Not Apply
3. Exercising (for example, in general or fitness classes, gyms, sports) <i>Comments:</i>	Not at all	A little	Very	Does Not Apply
4. Getting help in case of emergency (for example, calling 911)  Comments:	Not at all	A little	Very	Does Not Apply
5. Going to healthcare provider appointments (for example, making, remembering the appointment, getting to the appointment)  Comments:	Not at all	A little	Very	Does Not Apply
6. Managing your diet and nutrition (for example, figuring out what to eat, tracking calories, keeping hydrated, preparing meals)  Comments:	Not at all	A little	Very	Does Not Apply
7. Managing medications (for example, getting prescriptions filled, remembering to take them)  Comments:	Not at all	A little	Very	Does Not Apply
8. Monitoring health (for example, blood pressure monitor, blood-glucose readers, weight, activity tracking)  Comments:	Not at all	A little	Very	Does Not Apply

# **Basic Daily Activities**

Topic	How Difficult is			
Bathing, showering, or grooming (for example, shaving, make-up, brushing teeth)  Comments:	Not at all	A little	Very	Does Not Apply
2. Dressing Comments:	Not at all	A little	Very	Does Not Apply
3. Eating or feeding yourself <i>Comments:</i>	Not at all	A little	Very	Does Not Apply
4. Moving around in your home <i>Comments:</i>	Not at all	A little	Very	Does Not Apply
5. Toileting Comments:	Not at all	A little	Very	Does Not Apply
6. Transferring (getting around your home, transferring in and out of bed, on and off the toilet, or in and out of the shower)  Comments:	Not at all	A little	Very	Does Not Apply