Preferences of NIA Alzheimer’s Disease Research Center participants regarding remote assessment during the COVID-19 pandemic

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Abstract

Introduction: During the COVID-19 pandemic, in-person research study visits were moved to an online format using a variety of communication platforms (e.g., Webex and Zoom). Increased technology use among older adults allowed for greater insight regarding the remote research study visit format.

Methods: A survey developed by the National Alzheimer’s Coordinating Center (NACC) was distributed among 12 Alzheimer’s Disease Research Centers (ADRCs). The COVID-19 Technology Accessibility Survey aimed to understand preferences of older adults regarding their research study visits and how they accessed the internet.

Results: Among 12 ADRCs, 2070 responses were received (mean age: 72.8 years [standard deviation (SD) = 10.4], mean education: 16.6 years [SD = 2.6], race/ethnicity: 85% White/non-Hispanic). Among respondents, those with some form of cognitive impairment were more likely to prefer remote research study visits (mild cognitive impairment [MCI] vs. normal [odds ratio (OR) = 1.40, P = 0.02] and dementia vs. normal [OR = 1.48, P < 0.01]). Respondents with cognitive impairment were also less likely to have interest in smartphone use during at-home study visits (MCI vs. normal [OR = 0.71, P = 0.02] and dementia vs. normal [OR = 0.63, P < 0.001]). Results were similar regarding tablet use (MCI vs. normal [OR = 0.73, P = 0.04] and dementia vs. normal [OR = 0.72, P = 0.01]). Geographical location was analyzed in terms of the percentage of respondents in each region who preferred remote research study visits: West, 51%; Midwest, 34%; South, 41%; and Northeast, 57% (P < 0.0001).

Discussion: Results from the study suggest that there is a growing interest in the remote research study visit format. Further studies will allow for greater understanding and development of this research format.

KEYWORDS
aging, cognitive impairment, COVID-19, remote research, technology
1 | INTRODUCTION

Alzheimer’s disease and related dementias (ADRD) research is an area of intense interest and need given the high rates of dementia and mild cognitive impairment (MCI) in older adult populations and the pressing need for developing effective treatments. This need will only grow with 55 million affected globally currently and 10 million new cases emerging each year.1 As a result, aging and dementia will increasingly become one of the largest factors for dependence among older adults globally.2 Thus, the importance of sustaining or even increasing ADRD research is crucial to address this major public health problem.

The ability to sustain ADRD research came into sharp focus in March of 2020 when much of the clinical research being conducted in North America was halted or substantially curtailed due to the COVID-19 pandemic. A major reason for this sudden change was the result of ADRD clinical research relying on in-person clinical and cognitive assessments, which became untenable for safety reasons. As a way to overcome this limitation, methods of research administration transitioned to remote digital communications formats (i.e., video conferencing or telephone assessments) that had been studied and deployed in a number of pre-pandemic research studies.3–8 While this approach may be viable for many different populations, these approaches can present barriers to research when presented to different older populations and more dramatically older adults with cognitive impairment who may be less comfortable or willing to use technology, as well as having more limited access than younger adults.9–12 These concerns around technology use may be accentuated in older adults with cognitive impairment. However, little is known about the information-communication technology (ICT) preferences or capabilities of older adults specifically willing to participate in ADRD research. Although ICTs are increasingly adopted by the aging population, there is considerable heterogeneity in this adoption and use according to age. In a 2021 national American Association of Retired Persons (AARP) survey, 88% of those 60 to 69 years old owned a smartphone while ownership dropped to 72% in those aged 70 or older.13 There is a considerable discrepancy regarding confidence in using technology, with 31% of those age 70 or above uncertain as to their abilities compared to only 14% lacking confidence among those 60 to 69 years old.12 Lack of confidence or ability to use ICT is exacerbated by cognitive impairment. For example, people with MCI decrease their use technology as MCI progresses.14–16 Thus, although the ability to facilitate research using ICT to remotely assess individuals in an ADRD study has been found to be feasible, there remain questions as to how optimize this approach based on how ICT-based study assessments are perceived among older adults who may be enrolled in these clinical studies.

To better understand the ICT preferences and the technical capabilities of older adults participating in ADRD research, we evaluated the results from a survey of older adults with a range of cognitive status from normal to MCI to dementia participating as research volunteers in the National Institute on Aging (NIA)-supported 33 Alzheimer’s Disease Research Centers (ADRC) program. The survey addressed how the internet was accessed, the type of preferred research study visits, and the interest in the use of various technologies at home for study participation. This survey was intended to provide greater insight into the remote conduct of research study visits to guide how the experience can be improved and enhanced for future purposes.

2 | METHODS

The National Alzheimer’s Coordinating Center (NACC) collects data from 37 active ADRCs across 26 states in the United States to facilitate research in ADRD across a broad range of investigations.17 These centers represent the perfect organization of sites to adequately assemble this survey. As part of this effort, each center enrolls research participants into their regional center with each consenting participant undergoing a standardized assessment including demographics, health history and medical conditions, medications, functional status, depression scale, neurologic exam, a neuropsychological test battery, and clinician cognitive diagnosis.18 The collected data are sent and overseen by NACC. Prior to the COVID-19 pandemic these assessments were largely conducted in person. With the advent of the pandemic, this was no longer tenable and the ADRCs and NACC developed versions of their standardized assessment that could be administered remotely, either by telephone or video conferencing. As part of this pivot to remote assessment, a committee representing the ADRCs...
and NACC developed a survey (the COVID-19 Technology Accessibility Survey or CTAS [available in supporting information]) to better understand the capabilities and preferences of ADRD participants for conducting remote visits. All ADRCs that submitted the CTAS obtained informed consent from their participants to collect this data. The survey was provided to all ADRCs on July 2, 2020 as a new, optional (i.e., not all ADRCs were required to query their research cohorts) NACC form. As a result, this study aimed to gather data via a convenience sample as the provided data were from an optional source and targeted the specific demographic of aging adults. Instructions included that the form should be filled out by either the participant (if their Clinical Dementia Rating [CDR] score = 0 or 0.5) or by the co-participant/caregiver on behalf of the research participant (if CDR score > 0.5). Alternatively, the survey could be administered by study personnel. Instructions given to participants were: “We are asking these questions because COVID-19 has presented new challenges in continuing your visits with us. It has led to ideas on what to do now and maybe even in the future. As a research participant, you may decline to answer any of these questions, and it is all right to do so, but please answer as many of the questions as you feel comfortable with.” This survey asked specifically about remote research study visit preference, what devices respondents used to access the internet, whether they use e-mail to send and receive documents, and whether respondents were interested in smart homes and wearable devices. Cognitive status of respondents was determined using their clinical diagnosis from their on-site ADRC study visit closest to their survey completion.

Twelve geographically diverse ADRC sites administered the CTAS to their older adult volunteers during the time period of August 1, 2020 through November 15, 2021 (three West, five Midwest, two South, and two Northeast).

3 | STATISTICAL ANALYSIS

The final dataset (survey results, demographics, and cognitive status) from NACC was received on November 15, 2021. Chi-square ($\chi^2$) tests of independence were used to examine differences in categorical variables by cognitive status. Analysis of variance (ANOVA) was used to examine differences in continuous variables by cognitive status. Five multivariate logistic regression models were built to estimate the association between cognitive status and (1) remote visit preference, (2) interest in smartphone use, (3) interest in tablet use, (4) interest in desktop use, and (5) interest in laptop use after adjusting for covariates age, sex, race, education, and geographic region.

Statistical analysis was performed using SAS 9.4 software.

4 | RESULTS

Twelve ADRC sites collected 2070 survey responses from older adults with a range of cognitive status: normal cognition ($n = 1472, 71\%$), MCI ($n = 260, 13\%$), and dementia ($n = 338, 16\%$). Overall mean age was 72.8 years (standard deviation [SD] = 10.4), mean education was 16.6 years (SD = 2.6), 56% were female, and 15% were non-White. These results are summarized in Table 1.

Our study cohort who completed the CTAS is approximately 12% of the total active participants in the NACC database during the same time period (i.e., a convenience sample of all NACC participants). Volunteers who completed the survey had similar distributions of sex (56% vs. 59% female) and race (85% vs. 80% White) than those who did not. Mean age of those who completed the survey was similar to those who did not (73.5 years vs. 74.3 years). Those who completed the survey were more likely to be cognitively normal (71% vs. 51%) than those who did not. Overall, 35% of respondents would prefer an in-person study visit, 43% would prefer a remote study visit (telephone or video), and 22% had no preference. Cognitively normal respondents were more likely to access the internet via smartphone ($P = < 0.0001$), tablet ($P = 0.02$), laptop ($P = < 0.01$), or desktop ($P = 0.07$) than cognitively impaired respondents (see Table 1). Cognitively normal respondents were more likely to use e-mail than cognitively impaired respondents ($P = < 0.0001$) although e-mail use was high for all groups (87%). Cognitively normal respondents showed more interest in using smartphone ($P = < 0.0001$), tablet ($P = < 0.001$), laptop ($P = < 0.0001$), desktop ($P = < 0.01$), or wearables ($P = < 0.0001$) at home as part of their study visit than cognitively impaired respondents. Generally, respondents accessed the internet via smartphone and laptop, and less so via tablet and desktop. Overall, 18% of respondents were open to using a wearable device. Additionally, only 6% of respondents were willing to use smart home technology in the context of study visits.

After adjusting for covariates, respondents with cognitive impairment were more likely to prefer a remote study visit (telephone or video call vs. in person or no preference): MCI versus normal, odds ratio (OR) = 1.40, $P = 0.02$; and dementia versus normal, OR = 1.48, $P < 0.01$ (Table 2). Female respondents were more likely to prefer a remote study visit as well (OR = 1.27, $P = 0.01$). Cognitively impaired respondents were less likely to show interest in smartphone use during study visits compared to cognitively normal respondents with MCI versus normal (OR = 0.71, $P = 0.02$) and dementia versus normal (OR = 0.63, $P < 0.001$). Similar to smartphones, cognitively impaired respondents were less likely to show interest in tablet use during study visits compared to normal respondents: MCI versus normal (OR = 0.73, $P = 0.04$) and dementia versus health (OR = 0.72, $P = 0.01$). Older age was significantly associated with a lower likelihood of interest in smartphone or tablet use during a study visit. Education and race were not associated with remote visit preference or interest in smartphone or tablet use as part of the study visit. As shown in Table 2, Model 4, dementia volunteers were significantly less likely to show interest in desktop use during study visits (OR = 0.69, $P = < 0.01$). As shown in Table 2, Model 5, cognitively impaired volunteers were less likely to show interest in laptop use during study visits: MCI versus healthy (OR = 0.66, $P < 0.01$) and dementia versus healthy (OR = 0.66, $P < 0.01$). Older age was negatively correlated with interest in laptop use and higher education was positively correlated with interest in laptop use.

As a post hoc analysis, Model 1 (remote visit preference [telephone or video call] vs. other [in person or no preference]) was rerun with adjustments added for (1) smartphone and tablet current use and (2)
TABLE 1 Participant demographics and COVID-19 Technology Accessibility Survey results by cognitive status (n = 2070 from 12 ADRCs)

| Variables                                | Total n = 2070 | Normal cognition n = 1472 | MCI n = 260 | Dementia n = 338 | P-value |
|-------------------------------------------|----------------|----------------------------|-------------|------------------|---------|
| Age, years                                | 72.8 (10.4)    | 72.2 (10.3)                | 76.3 (9.0)  | 72.5 (11.3)      | <0.0001 |
|_sex: female, %                            | 56%            | 61%                        | 44%         | 43%              | <0.0001 |
| Education, years                          | 16.6 (2.6)     | 16.5 (2.5)                 | 16.1 (2.7)  | 15.9 (2.8)       | <0.0001 |
| Race/ethnicity                            |                |                            |             |                  |         |
| Asian                                     | 2%             | 2%                         | 1%          | 2%               | 0.02    |
| Black                                     | 12%            | 13%                        | 14%         | 7%               | ?       |
| Hispanic                                  | 3%             | 3%                         | 2%          | 2%               |         |
| White                                     | 82%            | 81%                        | 81%         | 89%              |         |
| Other                                     | 2%             | 2%                         | 2%          | 1%               |         |
| Geographic region                         |                |                            |             |                  |         |
| Midwest                                   | 50%            | 52%                        | 50%         | 47%              | <0.0001 |
| Northeast                                 | 20%            | 15%                        | 18%         | 39%              |         |
| South                                     | 10%            | 13%                        | 2%          | 3%               |         |
| West                                      | 20%            | 20%                        | 29%         | 11%              |         |
| Study visit preference                    |                |                            |             |                  |         |
| In person                                 | 35%            | 35%                        | 38%         | 32%              | <0.0001 |
| Telephone                                 | 22%            | 21%                        | 25%         | 24%              |         |
| Video                                     | 21%            | 19%                        | 24%         | 27%              |         |
| No preference                             | 22%            | 25%                        | 13%         | 17%              |         |
| How do you currently access internet?*    |                |                            |             |                  |         |
| Smartphone                                | 67%            | 70%                        | 60%         | 59%              | <0.0001 |
| Tablet/iPad                               | 42%            | 44%                        | 37%         | 37%              | 0.02    |
| Laptop                                    | 60%            | 62%                        | 52%         | 55%              | <0.01   |
| Desktop                                   | 41%            | 42%                        | 39%         | 35%              | 0.07    |
| Use e-mail to receive and send documents? |                |                            |             |                  | <0.0001 |
| Interest in using technologies for home study visit?* | | | | | |
| Smartphone                                | 56%            | 60%                        | 47%         | 47%              | <0.0001 |
| Tablet/iPad                               | 39%            | 42%                        | 32%         | 32%              | <0.0001 |
| Laptop                                    | 56%            | 59%                        | 45%         | 49%              | <0.0001 |
| Desktop                                   | 36%            | 38%                        | 37%         | 28%              | <0.01   |
| Wearable device                           | 18%            | 21%                        | 14%         | 8%               | <0.0001 |
| Smart home device                         | 6%             | 7%                         | 5%          | 6%               | 0.32    |

*Check all that apply.

Abbreviations: ADRC, Alzheimer’s Disease Research Center; MCI, mild cognitive impairment.

The percentages of respondents in each region who preferred remote (video or telephone calls) visits to in person visits were: West, 51%; Midwest, 34%; South, 41%; and Northeast, 57%; P < 0.0001. After adjusting for covariates, Midwest and South regions were significantly less likely to prefer a remote visit compared to the West (P < 0.0001 and P = 0.04, respectively). However, the Midwest was more likely to
| Variables                  | Model 1 |         |        |
|---------------------------|---------|---------|--------|
|                           | OR      | 95% CI  | P-value|
| MCI vs. healthy           | 1.40    | 1.05–1.85 | 0.02   |
| Dementia vs. healthy      | 1.48    | 1.15–1.91 | 0.003  |
| Female vs. male           | 1.27    | 1.06–1.54 | 0.01   |
| White vs. other race      | 0.90    | 0.69–1.16 | 0.41   |
| Age                       | 1.01    | 1.00–1.02 | 0.22   |
| Education                 | 1.00    | 0.98–1.01 | 0.67   |
| Midwest vs. West          | 0.51    | 0.40–0.65 | <0.0001|
| South vs. West            | 0.70    | 0.49–0.99 | 0.04   |
| Northeast vs. West        | 1.22    | 0.91–1.63 | 0.18   |

| Variables                  | Model 2 |         |        |
|---------------------------|---------|---------|--------|
|                           | OR      | 95% CI  | P-value|
| MCI vs. healthy           | 0.71    | 0.53–0.94 | 0.02   |
| Dementia vs. healthy      | 0.63    | 0.48–0.81 | <0.001 |
| Female vs. male           | 0.92    | 0.76–1.11 | 0.37   |
| White vs. other race      | 1.12    | 0.86–1.46 | 0.40   |
| Age                       | 0.96    | 0.95–0.96 | <0.0001|
| Education                 | 1.01    | 0.99–1.03 | 0.36   |
| Midwest vs. West          | 1.32    | 1.03–1.69 | 0.03   |
| South vs. West            | 1.34    | 0.94–1.90 | 0.10   |
| Northeast vs. West        | 0.79    | 0.59–1.06 | 0.12   |

| Variables                  | Model 3 |         |        |
|---------------------------|---------|---------|--------|
|                           | OR      | 95% CI  | P-value|
| MCI vs. healthy           | 0.73    | 0.54–0.98 | 0.04   |
| Dementia vs. healthy      | 0.72    | 0.55–0.93 | 0.01   |
| Female vs. male           | 1.18    | 0.98–1.42 | 0.09   |
| White vs. other race      | 1.25    | 0.96–1.62 | 0.10   |
| Age                       | 0.98    | 0.97–0.99 | <0.0001|
| Education                 | 1.01    | 1.00–1.03 | 0.18   |
| Midwest vs. West          | 1.18    | 0.92–1.51 | 0.19   |
| South vs. West            | 1.00    | 0.70–1.42 | 0.99   |
| Northeast vs. West        | 0.71    | 0.52–0.97 | 0.03   |

| Variables                  | Model 4 |         |        |
|---------------------------|---------|---------|--------|
|                           | OR      | 95% CI  | P-value|
| MCI vs. healthy           | 0.89    | 0.67–1.19 | 0.44   |
| Dementia vs. healthy      | 0.69    | 0.52–0.91 | <0.01  |
| Female vs. male           | 0.72    | 0.53–0.87 | <0.001 |
| White vs. other race      | 1.05    | 0.81–1.37 | 0.70   |
| Age                       | 1.00    | 0.99–1.01 | 0.56   |
| Education                 | 1.01    | 0.99–1.03 | 0.26   |
| Midwest vs. West          | 0.91    | 0.71–1.15 | 0.42   |
| South vs. West            | 0.67    | 0.47–0.95 | 0.03   |
| Northeast vs. West        | 0.36    | 0.26–0.49 | <0.0001|

(Continues)
show interest in smartphone use as part of the study visit compared to the West (P = 0.03). Northeast was less likely to show interest in tablet use as part of the study visit compared to the West (P = 0.03; Table 2).

5 | DISCUSSION

Results from 2070 older adults who completed the CTAS demonstrated a variety of preferences for remote study visits based on cognitive status, sex, age, and potentially geographic region. Respondents with MCI and dementia were more likely to prefer remote visits compared to those with normal cognition. Females were also more likely to prefer a remote study visit. Respondents in the Midwest were less likely to prefer a remote study visit compared to West. This data reflects the potential regional or local cultural and social norms that may influence these results. To our understanding, no other journal articles reported this information on geographical location and study visit preference. In terms of the association with race (dichotomized by White vs. non-White) and remote study visits, our data were limited by sample size and a lack of diversity (15% non-White). One study noted that interest in different technologies such as wearable devices and smart home technology may be less favorable due to the context in which they can be deployed and the understanding of the capabilities of these technologies.

This study had a number of limitations. The survey being administered was optional with only 12 of 33 ADRCs contributing to the NACC survey call. Respondents are thus from a subsample of the ADRC centers. Therefore, the limited number of participating centers, coupled with the survey being distributed as optional by the participating centers, created a double layer of consideration for respondents. Additionally, the sample was limited by convenience. Data collected were aimed at targeting the specific demographic of aging adults, and data with MCI and dementia. These results regarding technology use and accessibility remain consistent with a Pew Research Center study. Another study that looked at attitudes and use toward technology in cognitively impaired older adults found that those who were impaired used technology less, even though this population can achieve some of the greatest benefit from use. Furthermore, Wild et al. found that anxiety and competency around technology decreased when used over an extended period in older adults but saw less change in those with MCI and dementia. Older age was negatively associated with interest in smartphones or tablets at home during the study visit. Considering the wide array of devices used to access the internet, availability and accessibility would need to be present across all of the used platforms regarding remote research study visits. This would also allow for a “bring your own device” philosophy, which would make accessibility broader. The majority of survey respondents regardless of cognition use e-mail (87%); this suggests that e-mail is a good approach to delivering information or queries in research. For example, Oregon Center for Aging and Technology studies have successfully been deploying a weekly health form via e-mail for >10 years to a cohort of older adults but saw less change in those with MCI and dementia. Older age was negatively associated with interest in smartphones or tablets at home during the study visit.
provided were collected from this targeted group. Although there may be a regional bias there was a fairly even geographic representation among the ADRCs across the United States. Respondents’ answers may also have been influenced by the COVID-19 pandemic. This would call for an additional study conducted in the post-pandemic world to determine this consideration. The survey data were collected between August 1, 2020 and November 15, 2021. During this time information and instructions about the COVID-19 pandemic were rapidly changing. Depending on the date and pandemic rates and guidance at the time, the survey responses could have been affected. The sample lacked diversity; the majority were White (85%) and skewed toward being well educated. We did not have information on who (study participant or their caregiver/collateral) completed each form. Centers could choose to administer the survey by mail, e-mail, in person, or collect it over the phone/video. “Fillable” PDFs were provided to the centers to make data collection for remote visits easier. The method of administration was not captured. The CTAS could be administered at regularly scheduled study visits or at any other time.

The results of this study have the potential to inform the direction of future dementia research regarding mode of assessment and methodologies most likely to be adopted and successfully used. There is much heterogeneity in preferences for types of assessment and technologies used. It is important to address that there are many valuable uses to remote data collection; however, there are limitations via video and telephone visits, including the inability to perform certain aspects of neuropsychological tests that require the assessor and participant to be in the same room together. Several neuropsychological tests of visuospatial skills, executive function, and attention are unable to be completed via remote visit as well as some of the physical tests as part of the clinical exam. Other cognitive tests such as the Montreal Cognitive Assessment and Trail Making Test need to be modified for remote visits.

Technologic innovation and change are rapid, and future research needs to address more specific use cases and the rapidly changing landscape of remote assessment technologies to advance clinical research in ADRD.

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CONFLICTS OF INTEREST

Oregon Health and Science University and Z. Beattie have a financial interest in Life Analytics, Inc., a company that may have a commercial interest in the results of this research and technology. This potential conflict of interest has been reviewed and managed by OHSU. Both Michael Nunnerley and Nora Mattek have no relationships/activities/interests to disclose. Author disclosures are available in the supporting information.

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SUPPORTING INFORMATION
Additional supporting information can be found online in the Supporting Information section at the end of this article.

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