

RESEARCH ARTICLE

Participant completion of longitudinal assessments in an online cognitive aging registry: The role of medical conditions

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Abstract

INTRODUCTION: This study aimed to understand whether older adults' longitudinal completion of assessments in an online Alzheimer's disease and related dementias (ADRD)-related registry is influenced by self-reported medical conditions.

METHODS: Brain Health Registry (BHR) is an online cognitive aging and ADRD-related research registry that includes longitudinal health and cognitive assessments. Using logistic regressions, we examined associations between longitudinal registry completion outcomes and self-reported (1) number of medical conditions and (2) eight defined medical condition groups (cardiovascular, metabolic, immune system, ADRD, current psychiatric, substance use/abuse, acquired, other specified conditions) in adults aged 55+ ($N = 23,888$). Longitudinal registry completion outcomes were assessed by the completion of the BHR initial questionnaire (first questionnaire participants see at each visit) at least twice and completion of a cognitive assessment (Cogstate Brief Battery) at least twice. Models included ethnocultural identity, education, age, and subjective memory concern as covariates.

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RESULTS: We found that the likelihood of longitudinally completing the initial questionnaire was negatively associated with reporting a diagnosis of ADRD and current psychiatric conditions but was positively associated with reporting substance use/abuse and acquired medical conditions. The likelihood of longitudinally completing the cognitive assessment task was negatively associated with number of reported medical conditions, as well as with reporting cardiovascular conditions, ADRD, and current psychiatric conditions. Previously identified associations between ethnocultural identity and longitudinal assessment completion in BHR remained after accounting for the presence of medical conditions.

DISCUSSION: This post hoc analysis provides novel, initial evidence that older adults' completion of longitudinal assessments in an online registry is associated with the number and types of participant-reported medical conditions. Our findings can inform future efforts to make online studies with longitudinal health and cognitive assessments more usable for older adults with medical conditions. The results need to be interpreted with caution due to selection biases, and the under-inclusion of minoritized communities.

KEYWORDS

aging research, Brain Health Registry, comorbidities, dementia, engagement, internet registry, neuropsychological tests, online, remote assessment, retention

1 | BACKGROUND

Advances in Alzheimer's disease and related dementias (ADRD) research, especially in clinical research related to preventing or slowing cognitive decline and the progression of ADRD, are often hindered by slow participant enrollment and failure to reach target enrollment.^{1,2} Recruitment registries have been established as one way of efficiently identifying, prescreening, and referring to studies.³⁻⁵ In the ADRD field, several registries exist that differ in terms of reach (e.g., local vs national), population of interest, and format.⁶⁻¹⁵ One of the priorities outlined in the "National Strategy for Recruitment and Participation in Alzheimer's Disease Clinical Research" is the assessment of registry performance.¹⁶ Registry performance metrics include but are not limited to, registry enrollment, registry engagement (e.g., baseline and longitudinal assessment completion), and referral success to other studies. Although many registries are successful at enrolling participants, engagement of enrolled participants often represents a challenge.^{12,15,17}

One ADRD-related registry is the University of California, San Francisco Brain Health Registry (BHR). BHR is a public internet-based registry that, in addition to referring participants to outside studies, also includes remote online longitudinal health and cognitive assessments of adults (18+ years).^{11,12} BHR has successfully enrolled more than 100,000 participants since its inception in 2014, but it has struggled with facilitating completion of baseline and longitudinal assessments.¹² Identifying factors that influence longitudinal completion of online assessments is essential for the development of novel, effective strategies to increase longitudinal completion of online

assessments in registries, and potentially in other online longitudinal studies. Although there is not yet sufficient evidence to support a specific theoretical framework for understanding and improving online longitudinal assessment completion in ADRD research,¹⁸ the National Institute on Aging's (NIA's) Health Disparities Framework¹⁹ calls attention to the importance of multiple factors including environmental, sociocultural, behavioral, and biological factors. A prior study of BHR engagement identified important associations in older BHR participants between sociodemographic characteristics (age, gender, race, ethnicity, education, self-reported memory concern) and registry engagement, as measured by completing certain registry tasks at least once or twice.²⁰ In terms of biological factors, although emerging evidence has suggested that the presence of medical conditions in older adults affects participation in in-clinic studies,^{21,22} this association has not yet been evaluated in ADRD registries. Clarifying these relationships offers an important opportunity to better understand how registries could be adapted to make them more usable for older adults with medical conditions.

The goal of this post hoc study was to build upon prior analyses by examining associations between self-reported medical conditions and BHR longitudinal assessment completion (defined as completing certain online registry assessments on at least two occasions) in older adults (55+ years). We tested the specific hypotheses that (1) self-reporting more diagnoses of medical conditions is associated with poorer longitudinal assessment completion in BHR and (2) specific types of medical conditions (e.g., psychiatric, ADRD) are associated with poorer longitudinal assessment completion in BHR. Because minoritized ethnocultural and socioeconomic communities are often

burdened by more medical comorbidities,^{23–26} we also explored whether the previously identified association between sociodemographic participant characteristics (ethnocultural identity and education) and online registry longitudinal assessment completion²⁰ remained after adjusting the model to account for the presence of medical conditions.

2 | METHODS

2.1 | Study sample

This post hoc analysis used data from participants enrolled in the Brain Health Registry (or BHR). BHR is an online cognitive aging-related registry and longitudinal assessment platform that refers participants to outside studies. BHR also supports collection of study partner data. For more information about BHR, please see Weiner et al.^{11,12} The registry is approved by the University of California, San Francisco Institutional Review Board. The only inclusion criterion for joining BHR is that participants must be at least 18 years of age. Participants must also provide online informed consent and are not compensated. Participation includes the completion of self-report health and cognition-related questionnaires and cognitive assessments at 6-month intervals. At the time of the analysis, $N = 70,258$ participants were enrolled in BHR and of those, $N = 43,594$ were aged 55+ years. Of the participants aged 55+, there were $N = 23,888$ participants (54.8%) with data available for the medical condition variables (number of medical conditions reported, cardiovascular, metabolic, immune system, ADRD, current psychiatric, substance use/abuse, acquired, other specified conditions) and other participant characteristics (age, gender, education, ethnocultural identity, self-reported memory concern). Figure 1 shows a flow diagram of the number of participants excluded from this analysis, as well as a comparison of characteristics of participants with available data and those without available data. There were statistically significant differences in years of education, gender, ethnocultural identity, and self-report of subjective memory concern.

2.2 | Measures

2.2.1 | Participant characteristics

BHR collects self-reported demographic information from participants, and this analysis included age (continuous), gender (male, female), educational attainment (continuous, range: 6–20 years), ethnocultural identity (Latinx, non-Latinx Asian, non-Latinx Black, non-Latinx White, Other non-Latinx).

2.2.2 | Self-reported memory concern

BHR asks participants to self-report memory concerns by asking the following question: “Are you concerned that you have a memory problem?” The answer options are “yes” or “no.”

RESEARCH IN CONTEXT

- 1. Systematic review:** We used electronic databases (e.g., PubMed) and search engines (Google Scholar) to review the literature. Although emerging evidence has suggested that the presence of medical conditions in older adults affects participation in in-clinic studies, this association has not yet been evaluated in Alzheimer’s disease and related dementias (ADRD) registries.
- 2. Interpretation:** Our study provides novel initial evidence that medical conditions in older adults might influence their engagement in an online ADRD-related research registry, which is consistent with in-clinic data. However, results need to be interpreted with caution due to the present selection biases and under-inclusion of minoritized communities.
- 3. Future directions:** Future research should extend these findings by identifying other single or intersecting factors that might influence online registry engagement. Based on these findings, research is also needed to develop and evaluate tailored efforts to improve participation in ADRD research registries.

2.2.3 | Self-reported medical conditions

BHR contains a self-report questionnaire that asks participants about their medical history and to indicate whether they currently have or have had a specified condition (“Please indicate whether you currently have or have had any of the following conditions in the past...” with answer choices being “yes” or “no.” We created a continuous variable counting the number of reported medical conditions. In addition, we categorized the medical conditions into eight groups: cardiovascular, metabolic, immune system, ADRD, current psychiatric, substance use/abuse, acquired, and other specified conditions. See Table 1 for specific conditions included in each of the medical condition groups. These eight medical condition group variables were binary (yes vs no) and coded as follows: if a participant reported one or more of the conditions listed in the group, then the variable was coded as “yes,” and if the participant did not report any of the conditions within the group, then the variable was coded as “no.”

2.2.4 | Registry longitudinal assessment completion metrics

For this analysis, we defined longitudinal registry assessment completion as the completion of certain BHR tasks on at least two occasions, as in a previous analysis of BHR engagement.²⁰ BHR tasks include both online self-report questionnaires and cognitive assessments. We evaluated completion of self-report questionnaires and

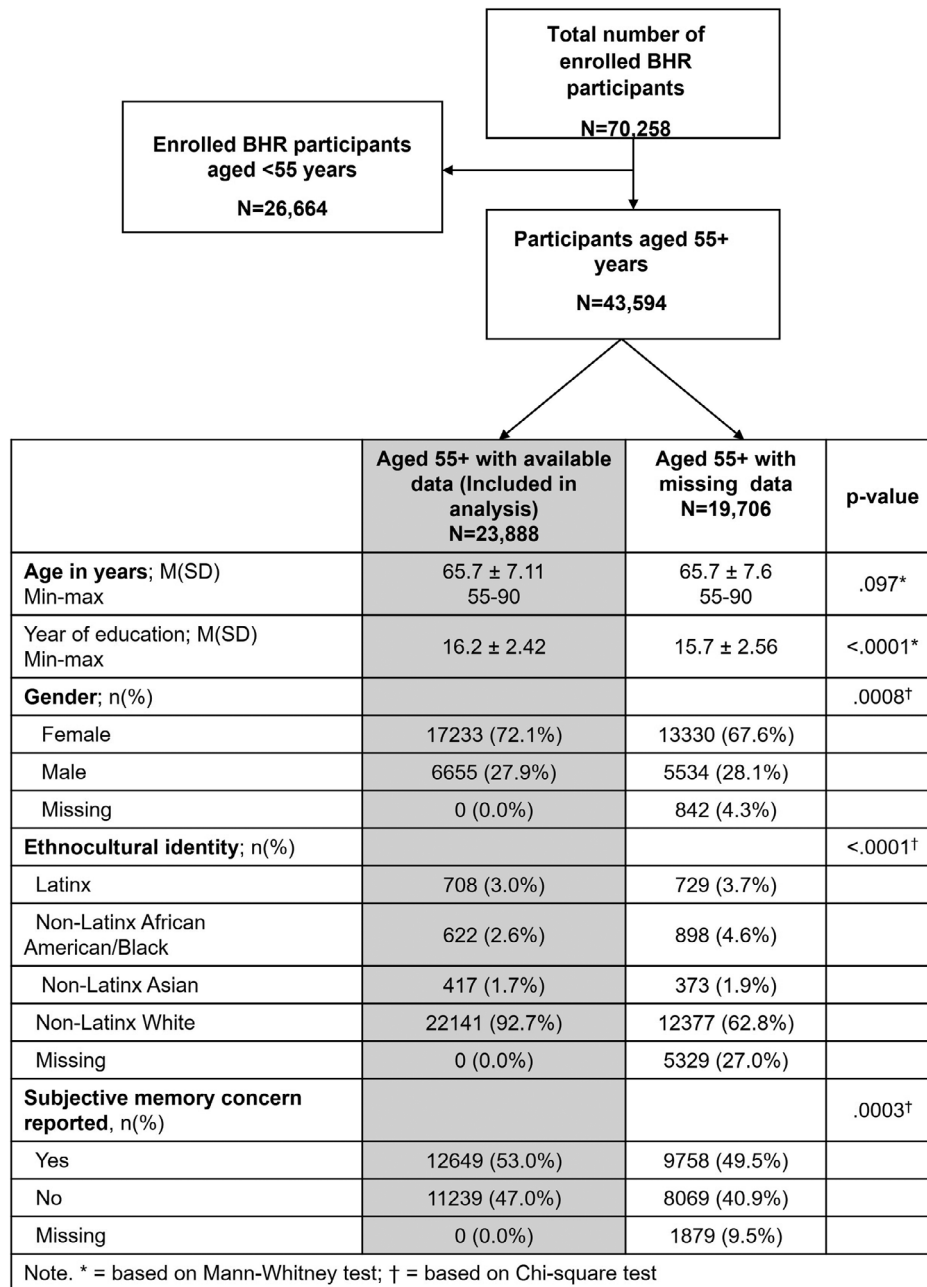


FIGURE 1 Flow chart of sample section and comparison of participant characteristics (included vs not included in analysis).

cognitive assessments as distinct measures. Specifically, self-report questionnaire engagement was determined by completion of the initial BHR questionnaire on at least two occasions. This questionnaire includes inquiries about participants' brief medical history and cognitive health and is administered at the beginning of each visit. The Cogstate Brief Battery, a cognitive assessment with validity in remote settings in cognitive aging and AD studies,²⁷⁻²⁹ was used as the measure of cognitive assessment task engagement. Both longitudinal engagement variables were binary (yes vs no) and coded as follows: if a participant completed at least two tasks in a category (self-report questionnaire or cognitive assessment), then the corresponding variable was coded as "yes," and if the participant had fewer than two tasks

completed in a category, then the corresponding variable was coded as "no."

2.3 | Statistical analyses

We summarized participant characteristics descriptively (categorical: n, percentage; continuous: mean, standard deviation [SD]). We assessed the model for the presence of multicollinearity by computing the variance inflation factors (VIFs) associated with each covariate. The resulting VIFs were low (range: 1.01-1.17), and multicollinearity was not deemed a concern. For each of the two longitudinal

TABLE 1 Medical condition groupings.

Cardiovascular conditions	Heart disease
	Stroke
	High blood pressure
Metabolic conditions	High cholesterol
	Diabetes
Immune system conditions	Lung disease
	Asthma
	Arthritis
	Multiple sclerosis
	Allergies
Acquired conditions	Traumatic brain injury
	Concussion
	Cancer
	Hearing loss
ADRDs	Alzheimer's disease
	Dementia
	Frontotemporal dementia
	Lewy body disease
Substance use/abuse	Alcohol abuse
	Drug abuse
	Smoked tobacco
Current psychiatric conditions	Current psychosis
	Current eating disorder
	Current schizophrenia
	Current autism
	Current bipolar disorder
	Current panic disorder
	Current generalized anxiety disorder
	Current posttraumatic stress disorder
	Current major depressive disorder
	Current specific/social phobia
	Current obsessive-compulsive disorder
Current hoarding disorder	
Current attention-deficit/hyperactivity disorder	
Other specified conditions	Sleep apnea
	Chronic pain

assessment completion outcomes, we fitted two logistic regression models. The first included the number of medical conditions reported and participant characteristics as predictors and the second the eight medical condition groups and participant characteristics as predictors. The outcome variables were longitudinal completion of the initial questionnaire and longitudinal completion of the cognitive assessment. We report the magnitudes of associations using adjusted odds ratios (aORs) and associated 95% confidence intervals (CIs). SAS 9.4 (SAS

TABLE 2 Descriptive statistics of BHR participants ≥ 55 years.

BHR participants ≥ 55 years of age (N = 23,888)	
Participant characteristics	
Age, mean (M), standard deviation (SD), range	65.7 (7.11) 55–90
Years of education, M (SD), range	16.2 (2.42) 6–20
Female gender, n (%)	17,233 (72.1%)
Ethnocultural identity, n (%)	
Latinx	708 (3.0%)
Non-Latinx African American/Black	622 (2.6%)
Non-Latinx Asian	417 (1.7%)
Non-Latinx White	22,141 (92.7%)
Subjective memory concern reported, n (%)	12,649 (53.0%)
Medical comorbidities	
Number of medical comorbidities, M (SD), range	4.57 (2.83) 0–21
Cardiovascular conditions reported, n (%)	10,359 (43.4%)
Metabolic conditions reported, n (%)	11,703 (49.0%)
Immune system conditions reported, n (%)	5,437 (22.8%)
Acquired conditions reported, n (%)	12,143 (50.8%)
ADRDs reported, n (%)	23,193 (97.1%)
Substance use/abuse reported, n (%)	11,111 (46.5%)
Current psychiatric conditions reported, n (%)	5,344 (22.4%)
Other specified conditions reported, n (%)	14,169 (59.3%)
Registry engagement	
Longitudinal completion of the initial questionnaire	17,953 (75.2%)
Longitudinal completion of the cognitive assessment	10,628 (44.5%)

Institute, Cary NC) and R version 4.2.1 were used for data set building and analysis.

3 | RESULTS

3.1 | Sample characteristics

For the $N = 23,888$ BHR participants aged 55+ (see Table 2), the mean age was 65.7 years ($SD = 7.11$), the mean years of education was 16.2 ($SD = 2.39$); 72.1% identified as female, 3.0% identified as Latinx, 2.6% identified as non-Latinx African American/Black, 1.7% identified as non-Latinx Asian, 92.7% identified as non-Latinx White, and 53.0% self-reported a memory concern. Participants self-reported an average of 4.6 medical comorbidities ($SD = 2.83$, $min = 0$, $max = 21$), 43.4% reported a cardiovascular condition, 49.0% reported a metabolic

condition, 77.2% reported an immune system condition, 2.9% reported an ADRD condition, 49.2% reported an acquired condition, 46.5% reported substance use/abuse, 22.4% reported a current psychiatric condition, and 40.7% reported at least one other unspecified condition.

3.2 | Online registry longitudinal assessment completion

In terms of engagement, 75.2% ($N = 17,953$) completed the initial questionnaire at least twice and 44.5% ($N = 10,628$) completed the cognitive assessment at least twice. (See Table 3 for a summary of the logistic regression models.)

3.2.1 | Association between the number of medical conditions and online longitudinal assessment completion

There was a statistically significant association between the number of medical conditions and the likelihood of having completed the cognitive assessment at least twice (aOR = 0.97, 95% CI: 0.96–0.98), but not for having completed the initial questionnaire at least twice (aOR = 0.99, 95% CI: 0.98–1.00). This implies that, after adjusting for the effects of the covariates, a unit increase in the number of self-reported medical conditions is associated with a 3% reduction in the odds of a participant having completed at least two cognitive assessments, relative to baseline.

3.2.2 | Association between different medical condition groups and online longitudinal assessment completion

We found that, holding all other predictor variables constant, the likelihood of having completed the initial questionnaire twice was negatively associated with having self-reported ADRD-related conditions (aOR = 0.27; 95% CI: 0.23–0.32) and current psychiatric conditions (aOR = 0.92; 95% CI: 0.85–0.99), but positively associated with reporting substance use/abuse conditions (aOR = 1.08; 95% CI: 1.01–1.14) and acquired conditions (aOR = 1.12; 95% CI: 1.05–1.19).

Holding all other predictor variables constant, the likelihood of completing the cognitive assessment twice was negatively associated with having self-reported cardiovascular conditions (aOR = 0.90, 95% CI: 0.85–0.96), ADRD-related conditions (aOR = 0.49, 95% CI: 0.41–0.58), current psychiatric conditions (aOR = 0.77, 95% CI: 0.72–0.82), and other specified conditions (aOR = 0.91, 95% CI: 0.86–0.96).

3.2.3 | Associations between sociodemographic characteristics and online longitudinal assessment completion

Across all models, accounting for medical conditions and other participant characteristics, self-identifying as Latinx and non-Latinx African

American/Black was associated with a lower odds of longitudinal completion of the initial questionnaire and cognitive assessment compared to participants self-identifying as non-Latinx White, and self-identifying as non-Latinx Asian was associated with lower odds of longitudinal completion of the cognitive assessment (see Table 3). In addition, every year of increase in education was associated with higher odds of longitudinal completion of the initial questionnaire and of the cognitive assessment in all models.

4 | DISCUSSION

Results showed that the likelihood of longitudinally completing the initial registry questionnaire was negatively associated with several self-reported medical condition groups in a cohort of participants enrolled in an online longitudinal research registry and with sufficient data for inclusion in this analysis. In addition, the likelihood of longitudinal cognitive assessment completion was associated with the number of self-reported medical conditions and several specific self-reported medical condition groups. The magnitude of the associations ranged from moderate to low. However, these findings provide initial support for the role of medical conditions in the completion of longitudinal assessments in online registries. It may also suggest the need for analysis plans to consider the potential effects of these factors (e.g., differential attrition, missingness not at random), as well as the need to take medical conditions into account when developing efforts to increase participation of older adults in online longitudinal research registries, and potentially other remote online longitudinal studies. However, compared to other remote longitudinal studies, registries with longitudinal assessments are unique, since the length of the longitudinal follow-up is open-ended rather than a pre-determined number of longitudinal follow-up points. This could also play a role in longitudinal assessment completion.

Our analysis found that the likelihood of longitudinal completion of the cognitive assessment is negatively associated with the number of participants' self-reported medical conditions. Although little is known about similar associations in other registries, our results are in line with in-clinic research that has identified health problems and multiple comorbidities as factors that impede study retention of older adults.^{21,22,30} Overall, participants with multiple medical conditions might experience additional burdens³¹; for example, more symptoms (e.g., pain, cognitive issues), logistical issues (e.g., coordinating frequent medical appointments and dealing with paperwork), and financial burden (e.g., greater health care costs), which might affect their ability or motivation to participate. However, we did not find the same association for longitudinal completion of the initial questionnaire. Compared to the completion of questionnaires, cognitive assessment completion, which requires the participant to concentrate on the assessment, might be more burdensome to participants with more medical symptoms, such as pain or cognitive issues.

When looking at certain types of self-reported medical conditions, the likelihood of longitudinal completion of the cognitive assessment decreases with self-reported cardiovascular, ADRD, current

TABLE 3 Estimated odds ratios and 95% confidence intervals from logistic regression models that assessed associations between predictors and BHR registry engagement outcomes.

	Longitudinal completion of the initial questionnaire	Longitudinal completion of the cognitive assessment
	Adjusted odds ratio (95% confidence interval)	Adjusted odds ratio (95% confidence interval)
Models with number of medical conditions + covariates		
Number of medical conditions	0.99 (0.98–1.00)	0.97 (0.96–0.98)*
Age	0.98 (0.97–0.98)*	0.99 (0.99–1.00)
Years of education	1.06 (1.05–1.08)*	1.07 (1.06–1.09)*
Male gender	0.90 (0.84–0.96)*	1.14 (1.08–1.21)*
Ethnocultural identity		
Non-Latinx White	1.0 (reference)	1.0 (reference)
Latinx	0.61 (0.52–0.72)*	0.61 (0.52–0.71)*
Non-Latinx African American/Black	0.52 (0.44–0.62)*	0.45 (0.38–0.54)*
Non-Latinx Asian	0.87 (0.69–1.08)	0.77 (0.63–0.94)*
Subjective memory concern reported	0.77 (0.72–0.81)*	0.88 (0.84–0.93)*
Models with medical condition groups + covariates		
Cardiovascular conditions reported	0.95 (0.89–1.01)	0.90 (0.85–0.96)*
Metabolic conditions reported	1.04 (0.97–1.11)	1.04 (0.98–1.10)
Immune system conditions reported	1.05 (0.98–1.14)	1.07 (1.00–1.14)
Acquired conditions reported	1.12 (1.05–1.19)*	1.06 (1.00–1.12)
ADRDs reported	0.27 (0.23–0.32)*	0.49 (0.41–0.58)*
Substance use/abuse reported	1.08 (1.01–1.14)*	0.99 (0.94–1.05)
Current psychiatric conditions reported	0.92 (0.85–0.99)*	0.77 (0.72–0.82)*
Other specified conditions reported	0.97 (0.91–1.03)	0.91 (0.86–0.96)*
Age	0.98 (0.97–0.98)*	0.99 (0.99–1.00)
Years of education	1.06 (1.05–1.07)*	1.07 (1.06–1.08)*
Male gender	0.93 (0.87–1.00)*	1.16 (1.09–1.23)*
Ethnocultural identity		
Non-Latinx White	1.0 (reference)	1.0 (reference)
Latinx	0.62 (0.53–0.73)*	0.62 (0.52–0.72)*
Non-Latinx African American/Black	0.53 (0.45–0.63)*	0.76 (0.62–0.93)*
Non-Latinx Asian	0.87 (0.69–1.08)	0.46 (0.38–0.55)*
Subjective memory concern reported	0.82 (0.77–0.87)*	0.92 (0.87–0.97)*
Models with has engaged study partner + covariates		
Has engaged SP	1.94 (1.78–2.12)*	3.48 (3.24–3.74)*
Age	0.98 (0.97–0.98)*	0.99 (0.99–0.99)*
Years of education	1.06 (1.04–1.07)*	1.06 (1.05–1.08)*
Male gender	0.86 (0.81–0.92)*	1.06 (1.00–1.12)
Ethnocultural identity		
Non-Latinx White	1.0 (reference)	1.0 (reference)
Latinx	0.63 (0.54–0.74)*	0.65 (0.55–0.76)*
Non-Latinx African American/Black	0.55 (0.47–0.65)*	0.50 (0.41–0.60)*
Non-Latinx Asian	0.90 (0.72–1.13)	0.84 (0.69–1.02)
Subjective memory concern reported	0.75 (0.71–0.8)*	0.83 (0.78–0.87)*

**p*-value < 0.05.

TABLE 4 Burdens related to medical conditions and potential approaches to facilitate longitudinal online assessment completion.

Potential burdens related to medical conditions	Potential approaches to facilitate longitudinal online assessment completion
Logistical burden—coordinating and attending frequent medical appointments	<ul style="list-style-type: none"> - Smartphone accessibility to make it easier to complete assessments while on the go. - Reduce overall length of assessments. - Allowing breaks between assessments.
Logistical burden—increase medical related paperwork	<ul style="list-style-type: none"> - Reduce overall length of assessments.
Financial burden—medical related bills	<ul style="list-style-type: none"> - Offering financial incentives for assessment completion to offset time spent on the assessment.
Symptom burden—issues with concentration	<ul style="list-style-type: none"> - Reduce overall length of assessments. - Allowing breaks between assessments.
Symptom burden—issues with cognition	<ul style="list-style-type: none"> - Offer personalized and/or automated reminders to complete follow-up visits. - Engage a study partner/caregiver who can help remind participants to complete assessments.

psychiatric, and other specified medical conditions. The likelihood of longitudinal completion of the initial questionnaire decreases with a self-reported diagnosis of ADRD and current psychiatric conditions. Our finding regarding ADRD conditions is consistent with results from longitudinal aging and cognitive aging-related studies, which have found that cognitive impairment was related to increased attrition.^{30,32,33} Regarding psychiatric conditions, common mental health-related symptoms—for example, reduced ability to concentrate, withdrawal from activities, fatigue, and low energy and motivation—might affect a participant's ability to complete registry tasks. In addition, previous research has found that participants with more depressive symptoms were more likely to drop out of longitudinal studies.³⁴ Self-reported diagnosis of an acquired medical condition and substance use/abuse were both associated with higher odds of longitudinal completion of the initial questionnaire. The interpretation of this is unclear; yet these results underscore the notion that certain medical conditions affect completion of online longitudinal assessments. However, more research is necessary to replicate these findings and to determine whether other potential factors might have contributed to the observed results in the current sample. In addition, future analyses should investigate the potential effects of the severity of the medical conditions on online longitudinal assessment completion and look at the differential contribution of specific psychiatric and ADRD conditions to longitudinal assessment completion.

It is also noteworthy that previously identified associations between sociodemographic participant characteristics (e.g., ethnocultural identity, education) and longitudinal assessment completion in BHR²⁰ remained after accounting for the presence of medical conditions. This explains some of the variability in the longitudinal assessment completion outcomes. Future analyses will investigate whether the associations between sociodemographic and longitudinal assessment completion in this registry are moderated by either the number of medical conditions or specific medical condition groups. This research could also be extended by identifying other single or intersecting factors that might influence online registry engagement. Identifying factors that contribute to research inclusion and completion, especially for minoritized communities (e.g., ethnocultural, socioeconomic), is a crucial need in the field, since they are often both under-included in ADRD

studies^{18,35} and disproportionately affected by ADRD.³⁶ In addition, minoritized ethnocultural communities experience more comorbidities compared to individuals who identify as non-Latinx White,^{23–26} and they experience a higher burden of dementia-related health care costs.³⁷ Aside from the medical conditions and covariates included here, there are several other potential factors that might affect the associations identified in our study. Such factors include other socioeconomic variables (household income, occupation), social and structural determinants of health, digital and health literacy, family history of AD, marital status, and enrollment source.

To facilitate online longitudinal completion of assessments of older adults with medical conditions, there is a need for developing creative approaches to alleviate the extra burden associated with medical conditions. Extra burdens related to medical conditions might include logistical burden (e.g., attending frequent medical appointments), financial burden (e.g., medical bill-related costs), as well as medical symptom burden (e.g., issues concentrating or issues with cognition). Table 4 outlines potential strategies that could be used to address these burdens; for example, making assessments smartphone accessible might aid participants who travel frequently to attend medical appointments (logistic burden) related to their medical conditions and minoritized communities who often rely more heavily on phones to access the internet.³⁸ Related to the medical burden of having issues with concentrating, reducing the overall length of assessments could facilitate completion. For example, at the time of the analysis, the estimated time to complete BHR was about 60 minutes, which might present a challenge for participants with medical conditions that affect concentration (e.g., some psychiatric conditions).³⁹ Follow-up, in-depth research with affected community members is needed to better understand their specific needs and burdens, which could then inform the development and adaptations of online registries. This could also include co-designing or adapting registries, which involves community members, other stakeholders, and scientists to work collaboratively to create, implement, and evaluate efforts.⁴⁰ One important issue to consider is that the longitudinal engagement studied here applies only to studies and registries that collect longitudinal data. It is not currently clear what participants want from their registry experience and whether a single interaction might get the participant what they want, for example, being registered to be informed about other research

opportunities. Future research could survey participants about what they want from a registry experience.⁴¹

This study is not without limitations. Multiple selection biases are present that affect the generalizability of the results. There are selection biases toward people who (1) are reached by recruitment efforts and who volunteer for research; (2) have computer and internet access and literacy; (3) speak English or Spanish; and (4) have sufficient data to be included in the analysis. Only 54% ($N = 23,888$) of enrolled BHR participants aged 55+ had sufficient data to be included in the analysis. Comparisons showed that there were significant differences between the participants included versus those excluded from the analysis. Regarding accessibility, BHR questionnaires are compatible across many devices, but the cognitive assessments currently can only be completed on a computer. This raises a concern for individuals from minoritized communities who are less likely to own a traditional computer and who, therefore, rely more often on their smartphone for internet access.^{38,42} On the other hand, participation in online research, like BHR, can be done at home and has considerably less participant time burden than studies requiring travel to clinics, invasive procedures (e.g., giving blood), or having scans. In addition, the present sample failed to include a representative number of adults who identify as Latinx, non-White, male, and adults from disadvantaged socioeconomic backgrounds. Furthermore, the limited sample of minoritized older adults might not represent the overall characteristics of each minoritized community. Finally, this study relied on self-reported medical diagnoses rather than clinically established diagnoses. In addition, there are different approaches to grouping medical conditions, which might lead to differences in identified associations. Furthermore, the multiple medical condition groups defined for this study contain conditions that might affect cognition, for example, depression, traumatic brain injury, or stroke. Additional analyses are needed to better understand the specific and differential effects of medical conditions on registry engagement.

Taken together, this post hoc study provides initial evidence that among older adults who enrolled in an online ADRD-related research registry and provided sufficient data, medical conditions affected longitudinal completion of online assessments. However, results need to be interpreted with caution due to the present selection biases and under-inclusion of minoritized communities. Nonetheless, these findings increase our understanding of factors affecting online longitudinal assessment completion in online registries, which could be relevant for other online longitudinal studies. The information gained here can inform future efforts to better understand how online longitudinal registries and other online longitudinal studies could be adapted to make them more usable for older adults with medical conditions.

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CONFLICTS OF INTEREST STATEMENT

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CONSENT STATEMENT

All participants in the Brain Health Registry provided informed consent by signing an electronic consent form.

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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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