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RESEARCH ARTICLE

Community-engaged efforts to increase retention of Black American online registry participants

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Abstract

INTRODUCTION: Many longitudinal Alzheimer's disease studies fail to retain Black American adults once enrolled. This limits the generalizability of research findings.

METHODS: The Community-Engaged Digital Alzheimer's Research (CEDAR) study developed digital, culturally-informed, community-engaged efforts to increase longitudinal registry task completion of Black American Brain Health Registry (BHR) participants. Difference-in-differences analysis was conducted to compare longitudinal registry task completion rates within groups (before vs. after CEDAR referral) and between groups (enrolled in CEDAR vs. not enrolled).

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RESULTS: Of 3888 invited Black American BHR participants, 420 (10.8%) enrolled in CEDAR. For CEDAR participants, we found significant increases in enrollment rate into referral studies and BHR timepoint completion rate after enrollment into CEDAR. Compared to those not enrolled, CEDAR participants had higher rates of: enrollment in referral studies, timepoint completion, initial questionnaire completion, and neuropsychological test completion.

DISCUSSION: The results provide preliminary evidence that CEDAR's culturally-informed, community-engaged research efforts were effective at improving engagement of Black American adults in an online longitudinal study. This is evidenced by increased registry engagement before and after enrollment and in comparison to Black American BHR participants not enrolled in CEDAR. These results need to be interpreted cautiously due to selection biases. This strategy can be adapted to other studies and settings.

KEYWORDS
Alzheimer's disease, Black/African American, brain health registry, community-engaged research, digital, effectiveness, engagement

Highlights

- CEDAR is an online AD/ADRD registry engagement intervention for Black participants.
- The intervention is community-engaged, digital, culturally-informed, and multifaceted.
- Engagement rates increased before versus during the intervention for enrollees.
- Engagement rates decreased over the same time period for non-enrolled participants.
- Results need to be interpreted with caution due to selection biases.

1 | BACKGROUND

Black/African American (hereafter referred to as Black American) older adults are affected by significant inequities in the incidence, prevalence, and outcomes of Alzheimer's and Disease Related Dementias (ADRD).[1–8] For example, Black American older adults have a 1.5- to 2x higher probability of developing dementia compared to non-Latinx White adults.[2,9] Despite the crucial need to better understand this increased risk, Black American older adults remain under-included in ADRD research, perpetuating ADRD inequities and limiting the generalizability and external validity of research findings.[10–16] In addition, many studies fail to engage (e.g., retain to study completion, complete all study tasks) Black American adults once enrolled.[17–24] It is critical to develop efforts that facilitate continued engagement of Black American adults in ADRD research.

Community-engaged research methods have proven effective for improving the inclusion of Black American adults in ADRD research.[25,26] Common methods used in community-engaged research include equitable partnerships between communities and scientists, listening/responding to the specific concerns of communities; and engagement with communities in an active and sustainable manner.[25,27,28] However, most community-engaged research methods are successfully deployed locally and in-person, thereby lacking scalability for larger multi-site studies or applicability to Internet-based studies.

Increasing numbers of older adults, including Black American older adults in the United States, have access to and use digital devices and the Internet.[29,30] However, there remains a digital divide in terms of access to technology. For example, approximately 28% of Black American adults do not have broadband Internet service at home, compared to 18% of White adults.[31] Nonetheless, the increasing accessibility and use offers an opportunity to use Internet-based approaches to increase research engagement. Advantages of Internet-based approaches include potential scalability and reduced costs, as well as the ability to engage participants who prefer or who can only be reached and participate in a remote setting. However, very little research has focused on developing and evaluating Internet-based efforts that use community-based

methods to increase research engagement in remote Internet-based settings.[28,32]

The aim of the Community-Engaged Digital Alzheimer's Research (CEDAR) study[33,34] was to develop and evaluate the effectiveness of remote, digital, culturally-informed, multifaceted, intensive community-engaged research (CER) efforts to increase engagement of Black American participants within the Brain Health Registry (BHR).[35,36] Like other ADRD related registries, BHR inadequately includes Black American adults. Only 4% ($N > 3700$) of BHR participants self-identify as Black American,[34] whereas 13.6% of the U.S. population self-identify as Black American according to the US Census.[37] Further, previous analyses have demonstrated BHR's failure to facilitate longitudinal registry engagement of enrolled Black American BHR participants.[23,24] We previously described the development and implementation of the CEDAR engagement intervention, including the establishment of a Black Community Science Partnership Board (CSPB), as well as reported interim results, including the number of Black BHR participants who were invited and enrolled in CEDAR, completed study and registry tasks after enrollment, and volunteered to join the CSPB, as well as compared participant characteristics, cognitive variables, and registry task completion rates between CEDAR participants and those invited to join the study but not enrolled.[34] This current analysis extends the prior analysis by focusing on longitudinal registry engagement. Specifically, we tested the hypothesis that the CEDAR engagement intervention would increase engagement of Black American adults in BHR. To do this, we compared how registry task engagement rates changed before and after exposure to the CEDAR engagement intervention in Black American BHR participants enrolled in CEDAR (intervention group). We further compared this change with the change over time in registry task engagement rates of Black American BHR participants who did not enroll in CEDAR and who were therefore not exposed to the CEDAR engagement intervention (control group). We also explored the participant utilization of two different engagement intervention components (Facebook group and 13-week email campaign).

RESEARCH IN CONTEXT

1. **Systematic review**: We reviewed the literature using electronic data bases (e.g., PubMed) and search engines (Google Scholar). Many Alzheimer's Disease and Alzheimer's Disease Related Dementias (AD/ADRD) studies fail to retain Black adults once enrolled. Yet, little research has focused on developing and evaluating digital efforts to engage Black participants in Internet-based longitudinal studies (including registries) which use community-based methods.
2. **Interpretation**: Our results suggest that a digital, culturally-informed engagement strategy incorporating community-engaged research methods can improve registry engagement of Black adults enrolled in an online AD/ADRD registry. Our results need to be interpreted with caution due to the presence of selection biases.
3. **Future directions**: Future research should extent these findings by identifying the comparative effectiveness of specific components of the intervention, or the intensity of engagement needed to be effective (the required "dose"). In addition, the effectiveness of the intervention needs to be evaluated using a randomized experimental design.

2 | METHODS

2.1 | Brain health registry CEDAR study

The CEDAR study developed and implemented culturally-informed CER digital efforts to increase registry engagement of Black American adults enrolled within the BHR[28,33,38] (see Methods S1 for more information about BHR). During the CEDAR study, BHR included a total of $N = 4469$ participants who self-identified as Black American. Of those, 3888 (86.99%) met the following eligibility criteria and were invited to join the CEDAR study using a series of automated, culturally-informed email invitations: currently enrolled in BHR and opted in to be informed about future research opportunities. Interested participants were presented with a culturally-informed website, which contained information about the study and led to an electronic informed consent document. Participants who completed the informed consent were considered enrolled. Upon enrollment, participants were presented with a brief survey about facilitators and barriers to participation in the BHR and preferred communication channels (see[33] for results from the survey). Participants were asked to indicate interest in joining a digital CSPB (see Method S2) and Ref. 38 for more information CSPB and its role in the study). Both the BHR and the CEDAR study are approved by the University of California, San Francisco, Institutional Review Board.

2.2 | CEDAR engagement intervention efforts

In close collaboration with our CEDAR CSPB, engagement intervention efforts for improving registry task completion of CEDAR participants were developed and deployed between July, 16 2021 and December, 31 2022 using a two-group (enrolled in CEDAR (intervention) versus not enrolled in CEDAR (control), two-timepoint design (before and after CEDAR referral/enrollment). Engagement strategies exclusive to the participants enrolled in CEDAR included financial compensation through gift cards for completing all registry tasks ($25–$50), access to a private Facebook group for current and prospective CEDAR participants to facilitate communication and share knowledge (a total of 12 posts were posted in the group by the study team), a 13-week email campaign which linked to new blog posts providing resources and educational materials about ADRD in the Black American community and was sent to all CEDAR participants, production of videos of participants sharing their motivations for joining/continuing

in and their experiences with BHR, and written testimonials from CEDAR participants about BHR. See Ref. 38 for more details about the different engagement efforts and Methods S3 for information about utilization metrics of two components of the CEDAR engagement intervention (Facebook group and email campaign) we explored in this analysis. The development of these efforts was culturally informed in that our CSPB members, study consultants, and one of our co-principal investigators, which guided our development, were all Black American adults.

2.3 | Participant characteristics

For this analysis, we used the following information self-reported by participants: age (continuous), gender (Male, Female, Other, Prefer not to say), years of education (continuous, range 6–20 years), Black American race (Black American only: self-identifies as Black American and no other race; More than One Race: self-identifies as Black American and at least one other race); Latinx/a/o ethnicity (Latino, non-Latino, Prefer not to say); endorsement of subjective memory concern (*"Are you concerned that you have a memory problem?"*); family history of Alzheimer disease/dementia, self-report of diagnosis of Alzheimer's disease, and mild cognitive impairment (MCI) or dementia.

2.4 | Registry engagement metrics

For registry engagement, we calculated completion rates for a variety of registry tasks by dividing the number of completed registry tasks by the number of available registry tasks. Registry tasks included in this analysis were: response, interest and enrollment in referrals, completion of the BHR initial questionnaire, neuropsychological tests (NPTs), and all registry task at one timepoint. Table 1 includes all registry engagement variables, their definitions, and calculations. We calculated the rates both for the time before and after being referred to CEDAR. Table S1 shows that both participants enrolled in CEDAR and participants not enrolled in CEDAR had similar number of available referrals, initial questionnaire and NPT assessments, as well as timepoints before and after CEDAR. We also defined a post-CEDAR referral engagement metric based on the initial questionnaire completion. The initial questionnaire is the first questionnaire shown to BHR participants at each timepoint. If participants completed the initial questionnaire at least once after CEDAR enrollment, this metric was coded as 1 and otherwise as 0.

3 | STATISTICAL METHODS

3.1 | Between-group analyses: Participant's metrics

We compared participant characteristics (Section 2.3) between Black American participants who enrolled in CEDAR and the Black American BHR participants who did not enroll. For continuous variables, independent sample *t*-tests were conducted to compare the group means. Cohen's *d* was reported as effect size. For categorical variables, χ^2 tests of independence were used if ≤20% of expected cell counts were less than 5. Otherwise, Fisher's exact tests were used.[39] Cramer's *V* was reported as effect size.

3.2 | Difference-in-differences analyses: Registry engagement metrics

We conducted difference-in-differences (DiD) analyses to compare registry engagement metrics between the participants who enrolled in CEDAR and the Black American BHR participants who did not enroll. In the absence of randomization, the DiD can identify the average treatment effect on the treated, which is the average outcome's difference between post-treatment and pre-treatment of the CEDAR group minus that of the BHR group.[40,41] The DiD requires the parallel trends assumption, meaning that if the participants in the CEDAR condition did not receive the CEDAR, their average changes of the outcomes from pre-treatment to the post-treatment would be the same as those of the comparison BHR condition. Participant age, years of education, and family history of Alzheimer's disease/dementia (0 = no, 1 = yes) were included as covariates because of the significant differences between the enrolled and not-enrolled participants.[34]

We also ran the DiD analysis without covariates and results were similar (see Table S2, Table S3, Table S4, and Figure S1 for results). Each registry engagement metric was analyzed in a separate model. In each model, participants who had the metric calculated before and after CEDAR were analyzed. Rates of missing values for age, years of education, and family history of Alzheimer disease/dementia in the models ranged from 0% to 3.5% (average missing rate = 0.6%). Full information maximum likelihood estimation was used to account for the missing values, assuming they were conditionally missing at random. Benjamini-Hochberg correction to false discovery rate was employed via the stats package in R.[42] Multilevel modeling was used to estimate each DiD model via M*plus* 8.8[43] (see Methods S4 for more information about the statistical model). As by-products from the analyses, we calculated the within-group differences before and after CEDAR for each group.

4 | RESULTS

4.1 | Between-group analyses: Participant characteristics

A total of 3888 Black American BHR participants were invited to join the CEDAR study. Of those invited, 420 (10.8%) enrolled in CEDAR. Participants enrolled in CEDAR were on average 63.09 (*SD* = 11.47) years old and reported 16.09 (*SD* = 2.39) years of education. The majority were female (*N* = 354; 84.29%). 80.95% (*N* = 340) self-identified as Black American only, 67.14% (*N* = 282) self-reported a memory

TABLE 1 Registry engagement variables, their definitions, and calculation.

Registry engagement metric	Definition	Calculation
Referrals	BHR participants are referred to additional studies, including observational remote/online studies, observational in-clinic, and experimental in-clinic studies.[36] Referrals to additional studies are made from the pool of enrolled BHR participants who have agreed to be contacted about future research opportunities. Self-reported information from the participant in BHR is often used to identify participants likely to be eligible for the referral study. Referrals emails describing the referral study and providing instructions for next steps are sent.	
Responded to referrals rate	Responded to the referral email by clicking on the embedded link in a referral invitation email.	Number of referrals responded to / number of referrals
Interested in referrals rate	Indicated interest in the referral study on a BHR landing page after having clicked the email link.	Number referrals indicated interest in / number of referrals
Enrolled in referrals rate	Referred participant enrolled in the available referral study.	Number of referrals enrolled in / number of referrals
Timepoint completion rate	Completed all available registry tasks (questionnaires and neuropsychological assessments) at a specific study timepoint (e.g., baseline, 6-month follow up, 12-month follow up).	Number of timepoints completed / number of timepoints
Initial questionnaire completion rate	Completed the initial questionnaires at a specific study timepoint. The initial questionnaire is the first questionnaire participants are presented with at each timepoint and includes sociodemographic information, self-reported diagnoses of MCI, dementia, and AD, family history of AD, self-reported memory concerns, and questions about cognition and mental health.	Number of completed initial questionnaires / number of initial questionnaires

Neuropsychological test (NPT) completion rate	Completed NPTs at a specific study timepoint. NPTs in BHR:
	• Cogstate Brief Battery [47]:
	  ○ Currently active in BHR
	  ○ Not available on smartphones
	  ○ Consists of four sub-tests
	  1) In the Detection task sub-test participants must respond as soon as the presented card changes.
	  2) In the Identification sub-test participants must decide as quickly as possible whether the presented card is red.
	  3) In the One-Card Learning sub-test participants must decide whether a presented card has been seen previously in the task.
	  4) In the One-Back sub-test participants must decide whether the card they are looking at is the same as the card that was presented on the immediately previous trial.
	• Cambridge Cognition Paired Associates Learning [48]:
	  ○ Currently active in BHR
	  ○ Not available on smartphones
	  ○ Participants need to remember the location of abstract colorful patterns which are presented within a variety of possible locations on a computer screen.
	• Memtrax Memory Test [49]:
	  ○ Currently discontinued, but was active during the CEDAR study
	  ○ Participants view a series of images and need to respond as quickly as possible whenever a repeated image appears.
	• Lumos Labs NeuroCognitive Performance Tests [50]:
	  ○ Currently discontinued
	  ○ Consists of eight standardized test batteries
		Number of completed NPTs / number of NPTs

concern, 40.71% ($N = 171$) reported a family history of AD, 8.81% ($N = 37$) self-reported a diagnosis of MCI, 3.57% ($N = 15$) self-reported a diagnosis of dementia, and 2.14% ($N = 9$) self-reported a diagnosis of AD. Compared to those who were invited but did not enroll in CEDAR ($N = 3468$), those enrolled (Table 2) were older ($p < 0.001$, Cohen's $d = 0.24$) and had higher education levels ($p < 0.001$, Cohen's $d = 0.28$). Those who enrolled also had a higher rates of family history of Alzheimer's disease/dementia ($p < 0.001$, Cramer's $V = 0.27$), self-reported diagnosis of MCI ($p < 0.001$, Cramer's $V = 0.24$), dementia ($p < 0.001$, Cramer's $V = 0.18$), and AD ($p < 0.001$, Cramer's $V = 0.15$). Of all enrolled CEDAR participants, 6 (0.15%) requested to be withdrawn from the CEDAR study. Results for the engagement intervention utilization metrics of the Facebook group and email campaign are reported in the Supplemental Results S5.

TABLE 2 Participant characteristics.

Variable	Participants invited to join CEDAR *N* = 3888	Participants enrolled in CEDAR *N* = 420	Participants invited who did not enroll in CEDAR *N* = 3468	95% Confidence interval	*p*-value from significant test between enrolled vs. not enrolled (effect size)
Age in years, M(SD)	60.37 (12.83)	63.09 (11.47)	60.05 (12.95)	−3.09, −3.01	<0.001 (0.24)*
Range	20–90	21–90	20–90		
Years education, M(SD)	15.45 (2.52)	16.09 (2.39)	15.38 (2.53)	−0.96, −0.47	<0.001 (0.28)*
Range	6–20	12–20	6–20		
Gender, *n* (%)				−0.05, 0.02	0.5 (0.04)†
Male	661 (17.00%)	66 (15.71%)	595 (17.16%)		
Female	3226 (82.97%)	354 (84.29%)	2872 (82.81%)		
Prefer Not to Say	1 (<0.01%)	0	1 (<0.01%)		
Ethnicity, *n* (%)				−0.03, 0.03	0.99 (0.005)†
Latino	329 (8.46%)	35 (8.33%)	294 (8.48%)		
Non-Latino	3441 (88.50%)	380 (90.48%)	3061 (88.26%)		
Declined to state	118 (3.03%)	5 (1.19%)	113 (3.26%)		
Race, *n* (%)				−0.06, 0.02	0.39 (0.05)†
Black American only	3211 (82.59%)	340 (80.95%)	2871 (82.79%)		
Black American mixed	677 (17.41%)	80 (19.05%)	597 (17.21%)		
Self-report memory concern, *n* (%)	2581 (66.38%)	282 (67.14%)	2299 (66.29%)	−0.04, 0.06	0.77 (0.02)†
Report family history of AD, *n* (%)	1147 (29.50%)	171 (40.71%)	976 (28.14%)	0.08, 0.18	<0.001 (0.27)†
Self-report diagnosis of MCI, *n* (%)	147 (3.78%)	37 (8.81%)	110 (3.17%)	0.03, 0.09	<0.001 (0.24)†
Self-report diagnosis of dementia, *n* (%)	48 (1.23%)	15 (3.57%)	33 (0.95%)	0.007, 0.05	<0.001 (0.18)†
Self-report diagnosis of AD, *n* (%)	28 (0.72%)	9 (2.14%)	19 (0.55%)	0.001, 0.03	<0.001 (0.15)†

*Independent sample *t*-test and Cohen's d.
†Chi-square test of independence or Fisher's exact test and Cramer's V.

4.2 | Difference-in-differences (DID) analyses: Registry engagement metrics

Tables 3 and 4 present the estimated means of the engagement metrics before and after the CEDAR study of the enrolled and non-enrolled participants with adjustment for covariates, respectively. Figure 1 shows mean plots of the engagement metrics before and after CEDAR for both groups of participants. For participants enrolled in CEDAR, there were significant increases in referral enrollment rate ($p < 0.001$, mean increase = 22.5%, Cohen's $d = 0.78$) and timepoint completion rate ($p < 0.001$, mean increase = 7.5%, Cohen's $d = 0.23$) after enrollment into CEDAR. For participants not enrolled in CEDAR, all the engagement metrics dropped to 0.0% ($ps < 0.001$, Cohen's d ranged from -0.90 to 0.00) after adjusting for covariates. See Supplemental material Table S2 and Table S3 for unadjusted engagement metrics.

Table 5 presents the difference in the change in registry engagement outcome over time (before-after) between groups who are enrolled and not enrolled in CEDAR (DiD estimate) of each registry engagement metric. Participants enrolled in CEDAR had significantly higher increase in the rates of enrollment in additional studies ($p < 0.001$, estimate = 22.5%, R^2 increase = 0.046), timepoint completion rate ($p < 0.001$, estimate = 9.3%, R^2 increase = 0.008), initial questionnaire completion rate ($p < 0.001$, estimate = 21.9%, R^2 increase = 0.007), and NPT completion rate ($p < 0.001$, estimate = 7.0%, R^2 increase = 0.000) than the participants not enrolled in CEDAR, after the end of the CEDAR study.

We conducted a logistic regression to understand the effect of CEDAR enrollment on post-CEDAR referral completion of the initial questionnaire, adjusted for the same set of covariates. CEDAR enrollment significantly improved the completion (odds ratio = 61.04, 95% CI = [44.43, 83.86]).

TABLE 3 Engagement metrics of enrolled CEDAR participants before and after joining the CEDAR study.

Engagement metric	*N*	Before CEDAR *M* (*SD*)	After CEDAR *M* (*SD*)	Mean difference (after−before)	95% Confidence interval	Unadjusted *p*	Adjusted *p*	Cohen's *d*
Responded to referrals rate	235	0.382 (0.434)	0.414 (0.383)	0.032	[−0.028, 0.093]	0.295	0.443	0.079
Interested in referrals rate	235	0.342 (0.420)	0.378 (0.367)	0.037	[−0.021, 0.095]	0.216	0.432	0.093
Enrolled in referrals rate	235	0.085 (0.246)	0.310 (0.326)	0.225	[0.180, 0.270]	<0.001	<0.001	0.779
Timepoint completion rate	335	0.193 (0.279)	0.268 (0.356)	0.075	[0.035, 0.114]	<0.001	<0.001	0.234
Initial questionnaire completion rate	346	0.598 (0.304)	0.612 (0.379)	0.014	[−0.028, 0.057]	0.509	0.509	0.042
NPT completion rate	350	0.365 (0.321)	0.379 (0.359)	0.014	[−0.022, 0.050]	0.450	0.509	0.041

Note. Benjamini-Hochberg method was used to correct the *p* values for multiple comparisons (multiple engagement metrics). Unadjusted *p* means the *p* values without the Benjamini-Hochberg adjustment, and adjusted *p* means the *p* values with the Benjamini-Hochberg adjustment. All analyses were adjusted for the following covariates: participant age, years of education, and family history of Alzheimer disease/dementia.

TABLE 4 Engagement metrics of participants not enrolled in CEDAR before and after the course of the CEDAR study.

Engagement metric	*N*	Before CEDAR *M* (*SD*)	After CEDAR *M* (*SD*)	Mean difference (after−before)	95% Confidence interval	Unadjusted *p*	Adjusted *p*	Cohen's *d*
Responded to referrals rate	2539	0.031 (0.222)	0.000 (0.140)	−0.031	[−0.041, −0.020]	<0.001	<0.001	−0.165
Interested in referrals rate	2539	0.021 (0.190)	0.000 (0.116)	−0.021	[−0.029, −0.013]	<0.001	<0.001	−0.133
Enrolled in referrals rate	2539	0.000 (0.086)	0.000 (0.104)	0.000	[0.000, 0.000]	<0.001	<0.001	0.000
Timepoint completion rate	3269	0.018 (0.100)	0.000 (0.063)	−0.018	[−0.022, −0.015]	<0.001	<0.001	−0.218
Initial questionnaire completion rate	3321	0.205 (0.285)	0.000 (0.148)	−0.205	[−0.214, −0.195]	<0.001	<0.001	−0.901
NPT completion rate	3299	0.056 (0.147)	0.000 (0.069)	−0.056	[−0.061, −0.051]	<0.001	<0.001	−0.488

Note: Benjamini-Hochberg method was used to adjust the *p* values. Unadjusted *p* means the *p* values without the Benjamini-Hochberg adjustment, and adjusted *p* means the *p* values with the Benjamini-Hochberg adjustment. All analyses were adjusted for the following covariates: participant age, years of education, and family history of Alzheimer disease/dementia.

5 | DISCUSSION

The major finding of this study was that remote, digital, multi-faceted, culturally-informed intensive engagement efforts were effective at improving engagement of Black American adults in an Internet-based longitudinal study. This was demonstrated by increased engagement, defined as task completion in BHR and enrollment in additional research studies from BHR. DID analyses further demonstrated a positive "intervention effect" of the engagement intervention through significant increases in engagement metrics over time for those enrolled versus not enrolled in CEDAR. Collectively, these results suggest that a novel digital engagement strategy incorporating community-engaged research methods can improve engagement of Black American adults in ADRD research.

In this study, all BHR participants self-identifying as Black American were invited to a study within BHR called the CEDAR study. The CEDAR study included a multi-faceted "engagement intervention."[34] Of those invited, 420 (10.8%) enrolled in CEDAR. A relatively small number of CEDAR participants joined the Facebook group (n = 36), but the email campaign performed above average compared to industry benchmarks. In comparison, average open rates for the health industry are around 33%[44] and CEDAR's email campaign average open rate was 61%). We found that engagement levels of enrolled CEDAR participants increased from before versus during the

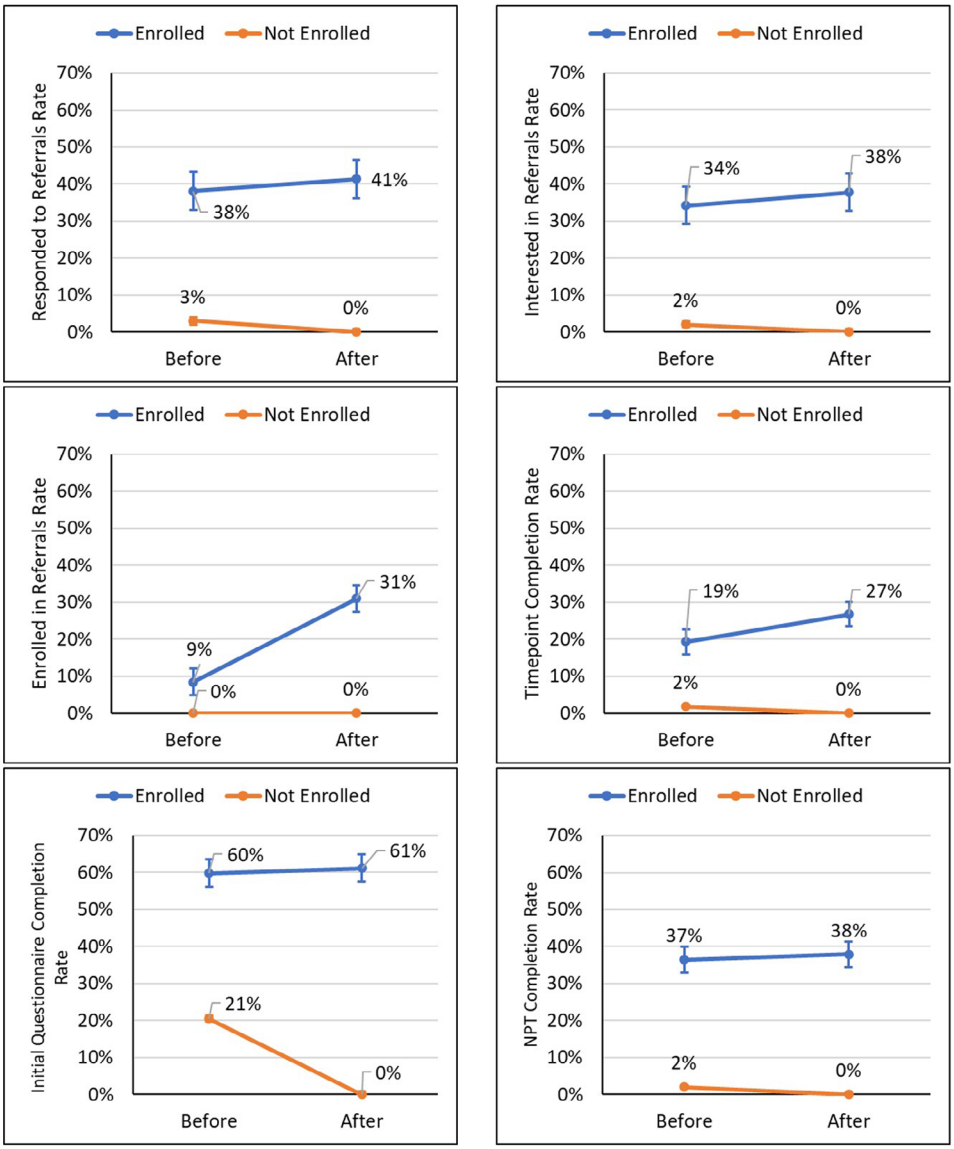

FIGURE 1 Difference-in-differences (DiD) analysis results for participant engagement metrics. Note. The error bar is the 95% confidence interval. All analyses were adjusted for the following covariates: participant age, years of education, and family history of Alzheimer's disease/dementia.

engagement intervention. Significant increases were found for the following engagement metrics: initial questionnaire completion, NPT completion, overall study timepoint completion. This finding suggests that the CEDAR intervention was effective at improving engagement of Black American adults in BHR. Furthermore, enrollment rates into additional research studies from BHR significantly increased from before versus during the CEDAR intervention. Since a major goal of BHR is to diversify ADRD and aging research, this is an important finding.

The DID analyses further demonstrate effectiveness of our approach. All engagement rates increased before versus during the intervention for enrolled participants, with effect sizes ranging from small to medium. Conversely, for those not enrolled in CEDAR, engagement across all metrics significantly decreased over the same time period. Compared to participants not enrolled in CEDAR, for CEDAR participants, the following engagement metrics significantly increased from before the CEDAR intervention to after the end of the intervention: enrolled in referrals rate, timepoint completion rate, initial questionnaire completion rate, and NPT completion rate, but not response and interest in referral studies rates. This result was most striking when evaluating enrollment in additional studies from BHR, where non-CEDAR enrolled participants had 0% additional enrollment, whereas CEDAR participants' enrollment rates increased from 1% to 23% (a median of 3% increase) over the course of the study. However, selection biases for CEDAR enrollment are an important consideration when interpreting this result. Since participants had to opt in to CEDAR by indicating their interest and enrolling before receiving the engagement intervention, the study design created a

TABLE 5 Difference-in-differences (DiD) estimates for engagement metrics of participants.

Engagement metric	DiD estimate	Standard error	95% Confidence interval	z	Unadjusted p	Adjusted p	R [2] increase
Responded to referrals rate	0.063	0.031	[0.002, 0.124]	2.012	0.044	0.053	0.0%
Interested in referrals rate	0.058	0.030	[-0.001, 0.116]	1.929	0.054	0.054	0.2%
Enrolled in referrals rate	0.225	0.023	[0.180, 0.270]	9.844	<0.001	<0.001	4.6%
Timepoint completion rate	0.093	0.020	[0.054, 0.132]	4.622	<0.001	<0.001	0.8%
Initial questionnaire completion rate	0.219	0.022	[0.175, 0.263]	9.771	<0.001	<0.001	0.7%
NPT completion rate	0.070	0.019	[0.033, 0.106]	3.759	<0.001	<0.001	0.0%

Note: DiD estimate is the causal effect average treatment effect on the treated, which is the average outcome's difference between post-treatment and pre-treatment of the CEDAR group minus that of the BHR group. Benjamini-Hochberg method was used to adjust the *p* values. Unadjusted *p* means the *p* values without the Benjamini-Hochberg adjustment, and adjusted *p* means the *p* values with the Benjamini-Hochberg adjustment. Covariates included participant age, years of education, and family history of Alzheimer disease/dementia.

selection bias for those already likely to be more engaged. In fact, we previously found that those who chose to enroll in CEDAR were already more engaged in BHR before the start of CEDAR.[34] Furthermore, our analyses uncovered additional selection biases likely to influence motivation to participate in BHR and additional studies. Those enrolled were older, self-reported more years of education, more family history of AD, as well as a higher percentage of self-reported diagnosis of mild cognitive impairment, dementia, and AD compared to those not enrolled (Table 2). Interestingly, initial response and interest in referral studies rates increased in CEDAR participants, but not significantly compared to non-CEDAR participants. It is unclear why these outcomes were refractory to our efforts while others were successful. However, this is an important future direction for research.

As previously noted in Gilmore-Bykovskyi's systematic review,[26] the evidence to inform best practices in the area of ADRD research recruitment is currently limited—in part due to the lack of rigorous, dedicated, prospective recruitment science studies and in part due to the even more acute paucity of research in the area of retention. Further, there is no research (outside of our previously published reports[33,38]) that has examined these issues within the area of Internet-based ADRD research. The CEDAR study addresses these current gaps in the literature as this was a comprehensive, prospective recruitment science study dedicated to examining whether community-engaged research methods could increase the engagement of Black American participants within an Internet-based ADRD research registry (the BHR). This represents a novel and important contribution to the literature. Given this study's design, it is not possible to specifically highlight which aspects of our comprehensive, multi-modal intervention may have been most effective for promoting study engagement within our sample.

Several limitations should be considered when interpreting our findings. The external validity/generalizability of our results is limited by several factors. First, the sample were Black American older adults with a relatively high level of education and predominately female. Second, several selection biases should also be considered, including that enrolled participants need to have access to a technological device and the Internet, speak either English or Spanish, be tech-savvy, and have the physical and cognitive capacity to interact with an unsupervised, remote assessment platform, which are important considerations among older adults. In addition, our analyses show additional selection biases for those who chose to join CEDAR from BHR. Regarding the internal validity of the findings, a number of important sociocultural characteristics were not included in these analyses because they were not collected as part of the BHR battery (e.g., socioeconomic status, quality of education, perceived discrimination, technological literacy, gender identity, sexual orientation) and represent important opportunities for future research. These characteristics could have provided greater context for the current findings. When investigating the engagement, we calculated rates of task completion to account for varying lengths of study participation of the CEDAR and non-CEDAR Black American BHR participants. However, we did not directly investigate how the varying length of enrollment in BHR and CEDAR before and after might have affected engagement. Future analysis should examine whether participants who recently interacted with BHR were more or less likely to respond to the intervention and whether there is a certain point in time at which the intervention fails to re-engage. In addition, it would be interesting to investigate engagement by age group. In relation to the study methodology, a further limitation was the non-randomized design. A randomized design would have allowed us to investigate causal effects without the parallel trends assumption, yet we opted for a within-group, pre–post design in order to pilot the feasibility and efficacy of our novel engagement intervention. Further, all of the engagement intervention components were implemented for all CEDAR participants simultaneously over the course of 15.5 months. Thus, we cannot draw conclusions about the comparative effectiveness of specific components of the intervention, or the intensity of engagement needed to be effective (the

required "dose"). In other words, the parallel trends assumption of the DiD is untestable in this study. Further, we only collected utilization data for two components of the engagement intervention. Collecting detailed utilization rates of the different engagement intervention components is an important future direction to help understand intervention effects and provide necessary information to replicate the study. In the future, the CEDAR engagement efforts could be expanded to all Black American BHR participants, as well as other communities, settings, and adapted for study recruitment. We are currently expanding our CEDAR efforts to the engagement of Latino adults in the BHR and will evaluate whether we can replicate our current findings. Future analysis could also investigate whether there were differences in BHR engagement among CEDAR participants who volunteered and were chosen to be part of the CEDAR CSPB and those who volunteered but were not chosen. In relation to the CSPB in this study, feedback was limited to development of the engagement intervention. Future studies should also elicit feedback from the CSPB on study methods and approach.

6 | CONCLUSION

The CEDAR study is the first to demonstrate the effectiveness of digital, CER efforts to improve retention and engagement of Black American older adults in an online longitudinal ADRD study. These methods can be adapted for use in additional ADRD and aging studies.

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CONFLICTS OF INTEREST STATEMENT

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CONSENT STATEMENT

All participants in the Brain Health Registry and the CEDAR study 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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