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RESEARCH ARTICLE

Retention of American Indian and Alaska Native participants in the National Alzheimer's Coordinating Center Uniform Data Set

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Abstract

INTRODUCTION: The number of American Indian and Alaska Native (AI/AN) elders is expected to double by 2060. Thus it is imperative to retain AI/AN participants in longitudinal research studies to identify novel risk factors and potential targets for intervention for Alzheimer's disease and related dementias in these communities.

METHODS: The National Alzheimer's Coordinating Center houses uniformly collected longitudinal data from the network of National Institute on Aging (NIA)–funded Alzheimer's Disease Research Centers (ADRCs). We used logistic regression to quantify participant retention at 43 ADRCs, comparing self-identified AI/AN participants to non-Hispanic White (NHW) participants, adjusting for potential confounding factors including baseline diagnosis, age, sex, education, and smoking.

RESULTS: The odds of AI/AN participant retention at the first follow-up visit were significantly lower than those for NHW participants (adjusted odds ratio [aOR]: 0.599; 95%: 0.46–0.78; $p < 0.001$).

DISCUSSION: These results suggest the need for improved strategies to retain AI/AN participants, perhaps including improved researcher–community relationships and community engagement and education.

KEYWORDS

American Indian and Alaska Native (AI/AN), Alzheimer's disease and related dementias (ADRD), Alzheimer's Disease Research Center (ADRC), data sovereignty, indigenous research, National Alzheimer's Coordinating Center (NACC), National Alzheimer's Coordinating Center Uniform Data Set (NACC UDS), Native American Elders, retention

Highlights

- American Indian and Alaska Native (AI/AN) research participants were retained to the first follow-up appointment at lower rates than non-Hispanic White (NHW) participants.
- AI/AN participants are retained at lower rates than NHW participants for long-term follow-up.

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- The majority of AI/AN participants were not retained to the second follow-up visit.

1 | INTRODUCTION

The U.S. Census Bureau estimates that the American Indian and Alaska Native (AI/AN) population of adults age 65 and over will nearly triple between 2016 and 2060.[1] Accordingly, estimates from the Centers for Disease Control and Prevention (CDC), Alzheimer's Association, and academic investigators are that the incidence of Alzheimer's disease and related dementias (ADRD) will increase four- to fivefold over the same time period in this group.[2–4] AI/AN populations already experience disparities in many health conditions,[5] including having the second highest dementia incidence rate among six racial and ethnic groups examined in one assessment of a large health care system.[6] Despite this, AI/AN patients are rarely recruited into ADRD research and are frequently grouped into an "Other" race/ethnicity category in research analyses. More specifically, AI/AN populations are especially underrepresented in clinical trials across the range of National Institutes of Health (NIH)–funded intervention studies.[7]

Barriers to AI/AN representation in research are numerous. Access to academic medical centers is limited by geography and sociopolitical constraints. Historical actions as well as research abuses[8] have created a setting where the field of research and even the word "research" are not viewed favorably in AI/AN communities.[9] Yet, little work has quantified recruitment and retention of AI/AN research participants.

To reduce the disproportionate burden of ADRD among AI/AN individuals, research must be inclusive of AI/AN communities. A systematic review of 22 identified studies that either (1) examined strategies for recruitment and retention of underrepresented populations in ADRD research or (2) reported on underrepresented participants' attitudes toward ADRD research, found that none focused on or included AI/AN populations.[10] Enrollment is, however, only one element of inclusive research. Kennedy et al., for example, analyzed 18 studies including clinical trials and observational studies and found that non-Hispanic Black participants had higher rates of attrition than did non-Hispanic White (NHW) participants.[11] Failing to retain participants throughout the course of a study can lead to decreased precision, questionable validity, and lack of generalizability of results.[12,13] Disproportionate loss to follow-up in specific groups may lead to low precision or biased results for those groups.

We assessed retention of AI/AN participants in ADRD research by comparing visitation patterns across racial and ethnic groups in the National Alzheimer's Coordinating Center (NACC) Uniform Data Set (UDS). The NACC UDS consists of longitudinal data collected at Alzheimer's Disease Research Centers (ADRCs) across the United States. Enrolled participants are expected to have annual follow-up visits at which a battery of clinical and cognitive assessments is used to arrive at a diagnostic status and to track performance over time. A major goal is to identify patterns of and risk for disease progression, making it an ideal data set for analyzing differences in participant retention. We hypothesized that, like other minority racial and ethnic groups,[11,14] AI/AN patients would have lower odds of study retention when compared to NHW participants.

2 | METHODS

2.1 | Study population

The NACC UDS consists of longitudinal demographic, clinical, neuropsychological, and diagnostic data on participants enrolled in National Institute on Aging (NIA)–funded ADRCs. Each center recruits participants according to their own protocol. Recruitment methods include clinical, family, and self-referrals, as well as community outreach and active recruitment. Conversely, core information on cognition, demographics, and participant health status is collected uniformly across all centers from participants and study partners directly on UDS forms with standardized evaluation by trained clinicians and clinic personnel. Enrolling with a study partner (e.g., spouse or adult child) is a requirement for participation, as study partners attend visits and complete informant-based assessments.

The current analysis utilized data from 43 ADRCs collected between September 2005 and November 2021. The initial diagnostic status of enrolled participants included normal cognition, impaired but not mild cognitive impairment (MCI), MCI, and dementia. Diagnoses were made by a single expert physician or a clinical team consensus, depending on site-specific ADRC protocols. Annual follow-up appointments generally occurred via in-person office visits. In response to the coronavirus disease 2019 (COVID-19) pandemic, additional options such as telephone and zoom visits were used to collect participant data. As part of the UDS, Milestone Forms[15] were collected to record participant dropout and death, as well as other major life changes (e.g., moving to a nursing home).

We classified participants into racial and ethnic categories based upon self-reported information and NIH definitions. Specifically, the NIH defines a person to be AI/AN if that is the only reported race. Selecting any race in addition to AI/AN categorizes that individual as "multiple races." To define our six race and ethnic groups, we first assigned participants based on their reported race with the categories AI/AN, Asian, Black, White, and Other/Multiple Races. We then distinguished Hispanic from non-Hispanic individuals for the White race category to create our final groups: AI/AN, Asian, Black, Hispanic White (HW), non-Hispanic White (NHW), and Other/Multiple Races. The "Other/Multiple Race" group consisted of 35 "Native Hawaiian or Pacific Islander" participants, 762 "Unknown or Ambiguous"

participants, 1392 "Multiracial" participants, and 128 White participants of "Unknown" Hispanic ethnicities.

Other covariates considered in our analysis were baseline diagnostic status, baseline age, binary sex, years of education, and smoking status. Baseline diagnostic status included "Normal cognition," "Impaired-not-MCI," "MCI," and "Dementia." Baseline age refers to the age of a participant at their initial visit. Binary sex refers to the participant's indication of being either male or female (no other options were available). Education categories were formed by discretizing "years of education" into: "Less than high school" for fewer than 12 years of education, "high school diploma/General Educational Diploma (GED)" for 12 years of education, "some college" for 13−−15 years of education, "4-year degree" for 16 years of education, and "greater than 4-year degree" for greater than 16 years of education. Smoking status (never, previous, and current) was created from participant self-reported answers to four questions: (1) at what age did the participant quit smoking, (2) total number of years the participant smoked, (3) has the participant smoked in the last 30 days, and (4) the average number of packs the participant smoked per day. Participants were assigned smoking status in the order of "never," "previous," "current," and "unknown." Participants were considered to have never smoked if they answered as never smoking or answered all questions as "Not applicable." Participants were considered to have previously smoked if they had a quit age, or an unknown quit age and did not smoke at the time, or an unknown quit age and a non-zero number of years as a smoker. Participants were considered to currently smoke if they had smoked within the last 30 days and had a non-zero number of packs smoked per day or had an unknown answer to questions 1, 2, and 4. The rest were considered "unknown."

RESEARCH IN CONTEXT

1. **Systematic review**: The authors searched traditional literature sources (e.g., PubMed) for research on the retention of underrepresented race and ethnicity groups in both Alzheimer's disease (AD) and non–AD-focused research. Historically, research has focused on non-Hispanic White (NHW) populations, leading to recruitment and retention tactics that primarily target and work in those populations—and not necessarily in other populations.
2. **Interpretation**: Our findings indicate that among research participants attending Alzheimer's Disease Research Centers (ADRCs), American Indian and Alaska Native (AI/AN) participants were retained at significantly lower rates when compared to NHW participants, after adjustment for potential confounders. This is consistent with previous work focusing on retention in underrepresented populations.
3. **Future directions**: The identification of culturally appropriate retention tactics for AI/AN participants in AD and other research is a crucial next step. We hypothesize that retention tactics will vary by tribe/nation and will be most successful with intimate relationships with tribes.

2.2 | Statistical methods

We assessed the retention of AI/AN participants in two ways: (1) the odds of retention at the first scheduled UDS follow-up and (2) the odds of retention at the next scheduled UDS follow-up visit having completed all previous follow-up visits, as defined per protocol. The first of our two analyses sought to determine if the odds of retention among AI/AN participants differed from that of NHW participants. We hypothesized that confounder-adjusted retention among AI/AN participants would be lower than that of NHW participants.

Because the ADRCs encourage annual appointments, the NACC defines participant retention as returning for a visit within 15 months of the previous visit's date. Choosing a more conservative window, we specified the retention versus dropout cutoff as 18 months. Under this definition in analysis (1), we considered a participant as retained if they attended a second visit within 18 months of their baseline visit. A participant who failed to return or returned for their first follow-up any time after month 18 was considered a dropout. In analysis (2), we counted a participant as retained if they had completed all previous visits within 18 months of the preceding visit. This definition means we considered a participant with a baseline visit and five annual follow-up visits followed by a 19-month gap (or greater) before the sixth follow-up visit to have been retained for five visits. Thus there are some participants who we considered a dropout per protocol, despite returning for further visits. In both settings, we removed all participants from the analysis sample who were not expected to return (e.g., participants enrolled as initial visit only).. Furthermore, in analysis (1), we only considered participants with at least 18 months of follow-up. In analysis (2), we censored participants at the minimum of time to death or end of follow-up.

To estimate the odds of retention at the first follow-up visit, we used logistic regression. To estimate the relative odds of retention at subsequent follow-up visits we used a continuation ratio model[16] with the timescale being number of visits (i.e., annual follow-up appointments attended). This model estimates the relative odds of completing a visit, conditional upon completing all prior visits. In both analyses, we adjusted for a priori hypothesized potential confounding factors. A covariate was a priori hypothesized to be a potential confounder if it was reasonably believed to be related to the probability of retention and related to race and/or ethnicity. Adjustment covariates included in both regression models included baseline diagnostic status, baseline age, binary sex, education categories, and smoking status as shown in Table 1. For all analyses we present point estimates along with corresponding 95% Wald-based confidence intervals (CIs) and p-values for the test of a null association. We assessed influence via Cook's distance. No individual points had outstanding influence compared to the others

TABLE 1 Descriptive statistics for National Institutes of Health (NIH) definition of race and ethnicity. Means (standard deviations) are reported for continuous variables. Frequencies (percents) are reported for discrete variables.

Characteristics	AI/AN *N* = 276 (0.6%)	Asian *N* = 1161 (2.6%)	Black *N* = 5697 (12.7%)	Hispanic White *N* = 2378 (5.3%)	Non-Hispanic White *N* = 32,884 (73.5%)	Other[a] *N* = 2317 (5.2%)
Mean baseline age	68.01 (10.63)	70.37 (10.29)	71.88 (8.99)	71.02 (10.11)	71.69 (10.68)	69.98 (10.53)
Binary sex						
Female	178 (64.5%)	678 (58.4%)	4088 (71.8%)	1552 (65.3%)	17,511 (53.3%)	1546 (66.7%)
Male	98 (35.5%)	483 (41.6%)	1609 (28.2%)	826 (34.7%)	15,373 (46.7%)	771 (33.3%)
Hispanic ethnicity						
No	228 (82.6%)	1146 (98.7%)	5537 (97.2%)	0 (0%)	32,884 (100%)	1118 (48.3%)
Yes	47 (17%)	11 (0.9%)	138 (2.4%)	2378 (100%)	0 (0%)	1024 (44.2%)
Unknown	1 (0.4%)	4 (0.3%)	22 (0.4%)	0 (0%)	0 (0%)	175 (7.6%)
Patient education						
<High school diploma	61 (22.1%)	88 (7.6%)	829 (14.6%)	792 (33.3%)	970 (2.9%)	649 (28%)
High school diploma/GED	105 (38%)	140 (12.1%)	1395 (24.5%)	474 (19.9%)	5540 (16.8%)	425 (18.3%)
Some college	54 (19.6%)	141 (12.1%)	1352 (23.7%)	389 (16.4%)	5673 (17.3%)	408 (17.6%)
4-year degree	28 (10.1%)	317 (27.3%)	851 (14.9%)	302 (12.7%)	8377 (25.5%)	360 (15.5%)
>4-year degree	25 (9.1%)	456 (39.3%)	1234 (21.7%)	402 (16.9%)	12082 (36.7%)	437 (18.9%)
Unknown/missing	3 (1.1%)	19 (1.6%)	36 (0.6%)	19 (0.8%)	242 (0.7%)	38 (1.6%)
Marriage status						
Married/partnered	145 (52.5%)	812 (69.9%)	2259 (39.7%)	1279 (53.8%)	23,224 (70.6%)	1162 (50.2%)
Previously married	114 (41.3%)	267 (23%)	2876 (50.5%)	941 (39.6%)	8016 (24.4%)	941 (40.6%)
Never married	15 (5.4%)	61 (5.3%)	488 (8.6%)	146 (6.1%)	1447 (4.4%)	172 (7.4%)
Other/unknown	2 (0.7%)	21 (1.8%)	74 (1.3%)	12 (0.5%)	197 (0.6%)	42 (1.8%)
Residence type						
Private residence	264 (95.7%)	1063 (91.6%)	5215 (91.5%)	2196 (92.3%)	29,403 (89.4%)	2143 (92.5%)
Independent community	2 (0.7%)	43 (3.7%)	256 (4.5%)	73 (3.1%)	1755 (5.3%)	71 (3.1%)
Assisted living	0 (0%)	26 (2.2%)	43 (0.8%)	24 (1%)	669 (2%)	28 (1.2%)
Nursing home	2 (0.7%)	5 (0.4%)	38 (0.7%)	26 (1.1%)	440 (1.3%)	16 (0.7%)
Other/unknown	8 (2.9%)	24 (2.1%)	145 (2.5%)	59 (2.5%)	617 (1.9%)	59 (2.5%)
Number of visits	2.39 (1.75)	3.36 (2.97)	3.38 (2.91)	3.24 (2.7)	3.82 (3.14)	3.11 (2.72)
Categorized number of visits						
<3	178 (64.5%)	621 (53.5%)	3033 (53.2%)	1250 (52.6%)	15,020 (45.7%)	1338 (57.7%)
≥3	98 (35.5%)	540 (46.5%)	2664 (46.8%)	1128 (47.4%)	17,864 (54.3%)	979 (42.3%)
Retention to follow-up 1 (within 18 months of initial visit)						
No	102 (44.5%)	349 (35.4%)	1945 (38.6%)	761 (36.5%)	8533 (29.4%)	742 (38.1%)
Yes	127 (55.5%)	636 (64.6%)	3098 (61.4%)	1322 (63.5%)	20,471 (70.6%)	1204 (61.9%)
Retention to follow-up 2 (within 18 months of F1)						
No	45 (38.5%)	160 (28.2%)	803 (29.1%)	311 (26.9%)	4166 (23.5%)	339 (32.3%)
Yes	72 (61.5%)	407 (71.8%)	1956 (70.9%)	846 (73.1%)	13,570 (76.5%)	709 (67.7%)
Baseline health status	AI/AN	Asian	Black	Hispanic White	Non-Hispanic White	Other[a]
Baseline diagnostic status						
Normal cognition	104 (37.7%)	487 (41.9%)	2533 (44.5%)	830 (34.9%)	12,839 (39%)	812 (35%)

(Continues)

TABLE 1 (Continued)

Characteristics	AI/AN N = 276 (0.6%)	Asian N = 1161 (2.6%)	Black N = 5697 (12.7%)	Hispanic White N = 2378 (5.3%)	Non-Hispanic White N = 32,884 (73.5%)	Other[a] N = 2317 (5.2%)
Impaired-not MCI	14 (5.1%)	51 (4.4%)	363 (6.4%)	133 (5.6%)	1260 (3.8%)	168 (7.3%)
MCI	57 (20.7%)	304 (26.2%)	1313 (23%)	608 (25.6%)	6977 (21.2%)	497 (21.5%)
Dementia	101 (36.6%)	319 (27.5%)	1488 (26.1%)	807 (33.9%)	11,808 (35.9%)	840 (36.3%)
Baseline primary etiology						
Cognitively normal	104 (37.7%)	487 (41.9%)	2533 (44.5%)	830 (34.9%)	12,839 (39%)	812 (35%)
Alzheimer's	97 (35.1%)	368 (31.7%)	1812 (31.8%)	901 (37.9%)	11,678 (35.5%)	866 (37.4%)
Lewy body	11 (4%)	21 (1.8%)	75 (1.3%)	47 (2%)	1299 (4%)	55 (2.4%)
Frontotemporal	1 (0.4%)	50 (4.3%)	52 (0.9%)	50 (2.1%)	1991 (6.1%)	72 (3.1%)
Vascular	7 (2.5%)	40 (3.4%)	226 (4%)	57 (2.4%)	511 (1.6%)	67 (2.9%)
Other reason	30 (10.9%)	118 (10.2%)	444 (7.8%)	266 (11.2%)	2069 (6.3%)	255 (11%)
Missing/unknown	26 (9.4%)	77 (6.6%)	555 (9.7%)	227 (9.5%)	2497 (7.6%)	190 (8.2%)
Family history of ADRD						
No	104 (37.7%)	499 (43%)	2245 (39.4%)	881 (37%)	11,900 (36.2%)	860 (37.1%)
Yes	111 (40.2%)	506 (43.6%)	2462 (43.2%)	1171 (49.2%)	17,634 (53.6%)	1100 (47.5%)
Unknown/missing	61 (22.1%)	156 (13.4%)	990 (17.4%)	326 (13.7%)	3350 (10.2%)	357 (15.4%)
Patient Independence						
Completely independent	173 (62.7%)	797 (68.6%)	4272 (75%)	1557 (65.5%)	21,031 (64%)	1457 (62.9%)
Some assistance needed	71 (25.7%)	216 (18.6%)	835 (14.7%)	432 (18.2%)	7416 (22.6%)	477 (20.6%)
A lot of assistance needed	23 (8.3%)	97 (8.4%)	423 (7.4%)	220 (9.3%)	2987 (9.1%)	243 (10.5%)
Completely dependent	6 (2.2%)	34 (2.9%)	152 (2.7%)	155 (6.5%)	1250 (3.8%)	93 (4%)
Unknown/missing	3 (1.1%)	17 (1.5%)	15 (0.3%)	14 (0.6%)	200 (0.6%)	47 (2%)
Diabetes status						
No	65 (23.6%)	318 (27.4%)	1138 (20%)	543 (22.8%)	7713 (23.5%)	459 (19.8%)
Yes	27 (9.8%)	80 (6.9%)	436 (7.7%)	180 (7.6%)	749 (2.3%)	134 (5.8%)
Missing	184 (66.7%)	763 (65.7%)	4123 (72.4%)	1655 (69.6%)	24422 (74.3%)	1724 (74.4%)
Smoking status	65 (23.6%)	318 (27.4%)	1138 (20%)	543 (22.8%)	7713 (23.5%)	459 (19.8%)
Never smoker	126 (45.7%)	888 (76.5%)	3109 (54.6%)	1510 (63.5%)	18,155 (55.2%)	1335 (57.6%)
Previous smoker	112 (40.6%)	233 (20.1%)	2032 (35.7%)	737 (31%)	12,948 (39.4%)	799 (34.5%)
Current smoker	31 (11.2%)	27 (2.3%)	447 (7.8%)	94 (4%)	1267 (3.9%)	139 (6%)
Unknown/missing	7 (2.5%)	13 (1.1%)	109 (1.9%)	37 (1.6%)	514 (1.6%)	44 (1.9%)
Body Mass Index categories						
Underweight	1 (0.4%)	53 (4.6%)	58 (1%)	30 (1.3%)	449 (1.4%)	22 (0.9%)
Normal	63 (22.8%)	601 (51.8%)	1201 (21.1%)	589 (24.8%)	11,291 (34.3%)	577 (24.9%)
Overweight	82 (29.7%)	298 (25.7%)	1763 (30.9%)	904 (38%)	11,157 (33.9%)	759 (32.8%)
Obese	106 (38.4%)	54 (4.7%)	2063 (36.2%)	652 (27.4%)	6138 (18.7%)	678 (29.3%)
Unknown/missing	24 (8.7%)	155 (13.4%)	612 (10.7%)	203 (8.5%)	3849 (11.7%)	281 (12.1%)
Number APOE ε4 alleles						
0	101 (36.6%)	592 (51%)	2071 (36.4%)	1146 (48.2%)	15,278 (46.5%)	901 (38.9%)
1	41 (14.9%)	190 (16.4%)	1465 (25.7%)	495 (20.8%)	8779 (26.7%)	496 (21.4%)
2	9 (3.3%)	33 (2.8%)	280 (4.9%)	61 (2.6%)	1773 (5.4%)	107 (4.6%)
Unknown/missing	125 (45.3%)	346 (29.8%)	1881 (33%)	676 (28.4%)	7054 (21.5%)	813 (35.1%)

(Continues)

TABLE 1 (Continued)

Characteristics	AI/AN N = 276 (0.6%)	Asian N = 1161 (2.6%)	Black N = 5697 (12.7%)	Hispanic White N = 2378 (5.3%)	Non-Hispanic White N = 32,884 (73.5%)	Other[a] N = 2317 (5.2%)
Study partner sex						
Female	185 (67%)	710 (61.2%)	3920 (68.8%)	1479 (62.2%)	20,063 (61%)	1547 (66.8%)
Male	67 (24.3%)	399 (34.4%)	1492 (26.2%)	740 (31.1%)	11065 (33.6%)	658 (28.4%)
Unknown/missing	24 (8.7%)	52 (4.5%)	285 (5%)	159 (6.7%)	1756 (5.3%)	112 (4.8%)
Study partner race						
AI/AN	136 (49.3%)	1 (0.1%)	9 (0.2%)	2 (0.1%)	26 (0.1%)	14 (0.6%)
Asian	1 (0.4%)	881 (75.9%)	10 (0.2%)	14 (0.6%)	260 (0.8%)	21 (0.9%)
Black	7 (2.5%)	8 (0.7%)	4882 (85.7%)	12 (0.5%)	144 (0.4%)	289 (12.5%)
Hispanic White	14 (5.1%)	6 (0.5%)	33 (0.6%)	1582 (66.5%)	361 (1.1%)	107 (4.6%)
Non-Hispanic White	63 (22.8%)	150 (12.9%)	185 (3.2%)	325 (13.7%)	29,600 (90%)	573 (24.7%)
Unknown/Missing/Other	55 (19.9%)	115 (9.9%)	578 (10.1%)	443 (18.6%)	2493 (7.6%)	1313 (56.7%)
Study partner education						
<High school diploma	25 (9.1%)	32 (2.8%)	305 (5.4%)	306 (12.9%)	391 (1.2%)	269 (11.6%)
High school diploma/GED	110 (39.9%)	103 (8.9%)	1184 (20.8%)	448 (18.8%)	4502 (13.7%)	457 (19.7%)
Some college	50 (18.1%)	121 (10.4%)	1319 (23.2%)	451 (19%)	5481 (16.7%)	440 (19%)
4-year degree	30 (10.9%)	376 (32.4%)	1151 (20.2%)	437 (18.4%)	8654 (26.3%)	452 (19.5%)
>4-year degree	21 (7.6%)	422 (36.3%)	1168 (20.5%)	448 (18.8%)	10506 (31.9%)	444 (19.2%)
Unknown/missing	40 (14.5%)	107 (9.2%)	570 (10%)	288 (12.1%)	3350 (10.2%)	255 (11%)

Abbreviations: AI/AN, American Indian and Alaska Native; APOE, Apolipoprotein E; ADRD, Alzheimer's disease and related dementias; GED, General Educational Diploma; MCI, mild cognitive impairment.

[a]The "Other" race category consists of 35 Native Hawaiian– or Pacific Islander–identifying participants, 762 participants with unknown race, 1392 multiracial participants, and 128 White participants with unknown Hispanic ethnicity.

The "Other" race category includes all individuals who identify as more than one race. This consists of 120 individuals who identify AI/AN as their primary race, 727 who identify AI/AN as their secondary race, and 94 who identify AI/AN as their tertiary race.

and hence no data were removed from our analyses. All analyses were performed using R Statistical Software (v4.1.0; R Core Team 2021).

We observed relatively small amounts of missing data. Age, sex, race, and cognitive status were collected completely. Educational status was missing for 332 participants and smoking status was missing for an additional 676 participants for a total of 995 of the 39,290 participants in the study (2.5%). Furthermore, only 8 of those 995 identified as AI/AN. Due to the small number of missing values, we conducted a complete case analysis for both aims.

We performed four sensitivity analyses to account for potential differential effects of the coronavirus disease 2019 (COVID-19) pandemic and to assess the potential for site-specific effects. To ensure that our definition of retention did not influence results, we conducted a sensitivity analysis where we did not censor participants that were seen more than 18 months after their prior scheduled visit (Supplementary Materials Section 1.1 [SM1.1]). To assess if the pandemic differentially impacted follow-up across race and ethnicity groups, we re-fit all models with a study end date of February 2020 (SM1.2). To assess potential site effects of retention, we repeated our analyses with only the sites that had any (>0) AI/AN participants and with only the sites that had at least 10 AI/AN participants (SM1.3). We assessed potential effect modification over time by splitting the cohort at the midpoint of the total observation period (pre-2013 vs post-2013).

3 | RESULTS

Table 1 describes the study sample. Descriptive statistics revealed some differences among the racial and ethnic groups at their baseline visit. Notably, AI/AN participants accounted for only 0.6% of participants. The other groups ranged from Asian participants (accounting for 2.6% of the sample) to NHW participants (accounting for 73.5% of the sample). AI/AN participants were observed to have the lowest level of formal education, with 60.1% of AI/AN participants self-reporting 12 or fewer years of education. There was a greater proportion of female participants versus male participants among all race and ethnicity groups. The AI/AN sample was 64.5% female-identifying, a higher proportion than the NHW participants (53.3%) but fewer than Black participants (71.8%). On average, AI/AN participants were the youngest (mean age of 68 years) at baseline. The AI/AN group included similar

proportions of participants enrolling with MCI (≈21%) and dementia (≈36%) to the NHW group. Although more than 90% of participants were currently or previously married (i.e., married, divorced, widowed, or separated), AI/AN (53%), Black (40%), and HW (54%) participants had lower current marriage rates when compared to NHW (71%) and Asian (70%) groups. Similar differences were observed for study partner relations. Thirty-nine percent of AI/AN, 30% of Black, and 39% of HW study partners were spouses, partners, or ex-spouses/ex-partners, compared to 61% for NHW and 55% for Asian co-participants. AI/AN participants had a higher observed rate of diabetes (10%) compared to all other groups, as well as double the frequency of obesity compared to NHW participants (38% vs 19%). AI/AN participants also had the highest rate of individuals who smoked (11%) among all racial and ethnic groups in the NACC UDS.

3.1 | Assessment of the odds of retention at the first follow-up visit

Among 38,409 participants, 26,346 (68.6%) attended an expected follow-up within 18 months of their initial visit. We observed that AI/AN participants were retained to first follow-up at the lowest rate (122 of 221 AI/AN [55.2%]) among all racial and ethnic groups (70.8% for NHW, 64.8% for Asian, 63.6% for HW, and 61.4% for Black participants). We used logistic regression to estimate the odds of retention at the first follow-up visit across racial and ethnic groups. Table 2 depicts the relative odds (and 95% Wald-based CIs) of retention for the race and ethnic groups after adjusting for potential confounding factors. We estimated that AI/AN participants had 40.1% lower relative odds of being retained to their first follow-up visit compared to NHW participants, after adjustment for baseline diagnostic status, age, sex, education level, and smoking status (adjusted odds ratio [aOR]: 0.599, 95% CI: 0.46–0.78; $p < 0.001$). There was no evidence of differential relative odds of retention for participants enrolled after 2013 compared to participants enrolled before 2013 (i.e., no cohort effect).

3.2 | Assessment of the odds of retention at all follow-up visits

Approximately one-fifth (19.7%) of the participants in the NACC data set were retained annually from their time of enrollment until either death or November 2021. In the four-fifths of participants who were not retained, we observed that the majority of their missed visits occurred soon after enrollment (within the first three follow-up appointments). Of the 243 AI/AN participants included in our analysis, 205 (84.4%) experienced a missed visit at some point during follow-up. Of the 38 AI/AN participants who did not miss an expected follow-up appointment, 11 (29%) were censored because they either died within 18 months of their previous assessment or attended a previous assessment within 18 months of the end of study follow-up. Of the 205 AI/AN participants who were not retained at an expected follow-up appointment, 103 participants were not retained at the first follow-up appointment, 47 were not retained at the second follow-up after having completed the first, and 27 were not retained at the third follow-up after having completed the first two visits. This accounts for 86.3% of the 205 AI/AN participants who missed a visit. In contrast, 71.5% of NHW participants missed the first, second, or third follow-up appointments. Based on the results of a continuation ratio model considering the relative odds of attending an annual visit within 18 months of the preceding visit, we estimated that compared to NHW participants, AI/AN participants had a 47% lower odds of being retained to their next visit, conditional on attending all previous visits (aOR: 0.53, 95% CI: 0.44–0.64). This comparison was adjusted for baseline diagnostic status, age, sex, education level, and smoking status. (See Table 3 for results.)

3.3 | Sensitivity analyses

To assess the impact of the COVID-19 pandemic on retention, we reran all analyses after adjusting the end-of-follow-up date to be February 2020. The overall retention rate for pre-COVID data was numerically higher (70.2%) than the main analysis proportion (68.6%). Of the 18 AI/AN participants who enrolled in the study within 18 months of February 2020, only 7 returned for their expected follow-up visit. We observed a retention rate of 56.2% for AI/AN participants who enrolled at least 18 months before COVID hit the United States, which is slightly higher than the previously observed 55.2% for the analysis that includes participants who enrolled within 18 months of the start of COVID. Results of the model for the outcome of retention to first follow-up remained nearly the same, with AI/AN participants having 40.1% lower odds of returning for the first follow-up appointment compared to NHW participants.

A second sensitivity analysis revealed that COVID impacted retention across all participants but did not exacerbate the differences between groups. In total, 4808 participants missed an expected follow-up after COVID (24 of whom were AI/AN participants), for an overall retention rate of 32.0% (22.1% for AI/AN participants). In this analysis, 92, 42, and 22 AI/AN participants were not retained to the first, second, and third follow-up visits, accounting for 90.2% of AI/AN participants who were not retained. Compared to NHW participants, AI/AN participants were retained for the long-term at a lower rate (33.9% NHW vs 22.1% AI/AN). Also similar to the full analysis, compared to NHW participants, AI/AN participants had an estimated 47% lower odds of being retained at an expected follow-up visit (aOR: 0.534, 95% CI: 0.44–0.65). (See SM 1.2 for details.)

To assess if potential effect-modification by site could account for lower retention among AI/AN participants, we restricted our analyses to two subsets of ADRCs. Figure 1 shows the odds ratios for retention to the first follow-up appointment across racial and ethnic groups compared to NHW participants from the analyses with all sites, the 24 sites with at least one AI/AN participant, and the five sites with at least 10 AI/AN participants. Although retention rates were not the same across sites, the overall results of the differences in retention of AI/AN participants relative to NHW remained consistent. Point estimates of

TABLE 2 Results for retention at first follow-up analysis.

Covariate	Unadjusted Odds ratio (95% CI)	Adjusted Odds ratio (95% CI)	Adjusted *p*-Value
Race/Ethnicity			
AI/AN	0.52 (0.40, 0.67)	0.60 (0.46, 0.78)	<0.001
Asian	0.76 (0.67, 0.87)	0.75 (0.66, 0.87)	<0.001
Black	0.66 (0.62, 0.71)	0.68 (0.64, 0.72)	<0.001
HW	0.72 (0.66, 0.79)	0.81 (0.74, 0.90)	<0.001
NHW	Referent	Referent	
Other[a]	0.68 (0.62, 0.74)	0.79 (0.71, 0.87)	<0.001
Baseline diagnostic status			
Normal	Referent	Referent	
Impaired-not MCI	0.83 (0.74, 0.92)	0.86 (0.77, 0.96)	0.008
MCI	0.80 (0.76, 0.85)	0.77 (0.73, 0.82)	<0.001
Dementia	0.66 (0.62, 0.69)	0.64 (0.60, 0.67)	<0.001
Age (×5 years)	1.08 (1.06, 1.09)	1.09 (1.08, 1.10)	<0.001
Sex			
Female	Referent	Referent	
Male	1.19 (1.14, 1.24)	1.16 (1.10, 1.21)	<0.001
Education (×4 years)	1.21 (1.18, 1.24)	1.12 (1.09, 1.15)	<0.001
<High school	Referent	Referent	
High school diploma/GED	1.22 (1.11, 1.33)	1.11 (1.01, 1.21)	0.038
Some college	1.37 (1.25, 1.50)	1.21 (1.10, 1.33)	<0.001
4-year degree	1.53 (1.40, 1.67)	1.27 (1.16, 1.40)	<0.001
>4-year degree	1.70 (1.56, 1.85)	1.36 (1.23, 1.49)	<0.001
Smoking status			
Never	Referent	Referent	
Former	1.14 (1.09, 1.19)	1.08 (1.03, 1.13)	0.002
Current	0.75 (0.68, 0.83)	0.89 (0.8,0 0.98)	0.023

Note: This table highlights the regression results for the retention to first follow-up model. The first column shows unadjusted relative odds (and 95% Wald-based confidence intervals (95% CI)) of retention for the defined race and ethnic groups and each of the adjustment variables. The second column depicts the relative odds (and 95% Wald-based confidence intervals (95% CI)) of retention for the race and ethnic groups after adjusting for each of the a priori specified potential confounders. The third column specifies the *p*-values associated with the adjusted analysis results. Adjusted estimates were based on 38,409 participants of which 26,346 were retained. Of these participants, 221 identified as AI/AN-only with 122 of them retained.

Abbreviations: AI/AN, American Indian and Alaska Native; GED, General Educational Diploma; HW, Hispanic White; MCI, mild cognitive impairment; NHW, non-Hispanic White.

[a]The "Other" race category consists of participants who identified as Native Hawaiian or Pacific Islander, unknown race, multiracial, or White participants with unknown Hispanic ethnicity.

retention rates compared to NHW were lower for AI/AN participants (as well as Black and HW participants) in the group of five sites with at least 10 AI/AN participants. (See SM1.3 for details.)

4 | DISCUSSION

We examined the rates of retention of AI/AN participants in the NACC UDS. We considered two definitions of participant retention: (1) the odds of retention to the first follow-up visit and (2) the relative odds of completing any follow-up visit having attended all previous follow-up visits. In both cases, AI/AN participants were retained at significantly lower rates when compared to NHW participants. Both sets of analyses had similar results regardless of the study end date, the exclusion of sites with limited numbers of AI/AN participants, or the adjustment for potential confounders.

In sensitivity analyses, we considered that COVID may have changed retention patterns. We observed that COVID impacted retention rates, but not enough to change the results of these analyses. It was noted early in the pandemic that COVID disproportionately

TABLE 3 Results of a regression model for the outcome of long-term follow-up.

Covariate	Unadjusted Odds Ratio (95% CI)	Adjusted Odds Ratio (95% CI)	Adjusted *p*-Value
Race/Ethnicity			
AI/AN	0.46 (0.38, 0.55)	0.54 (0.45, 0.66)	<0.001
Asian	0.78 (0.72, 0.85)	0.78 (0.72, 0.85)	<0.001
Black	0.72 (0.69, 0.75)	0.74 (0.71, 0.77)	<0.001
HW	0.66 (0.63, 0.70)	0.77 (0.72, 0.81)	<0.001
NHW	Referent	Referent	
Other[a]	0.67 (0.63, 0.71)	0.78 (0.73, 0.83)	<0.001
Baseline diagnostic status			
Normal	Referent	Referent	
Impaired-not MCI	0.81 (0.76, 0.86)	0.84 (0.79, 0.89)	<0.001
MCI	0.67 (0.65, 0.69)	0.65 (0.63, 0.68)	<0.001
Dementia	0.57 (0.55, 0.59)	0.58 (0.56, 0.59)	<0.001
Age (×5 years)	1.06 (1.05, 1.07)	1.07 (1.06, 1.08)	<0.001
Sex			
Female	Referent	Referent	
Male	1.12 (1.09, 1.15)	1.13 (1.10, 1.16)	<0.001
Education (×4 years)	1.21 (1.19, 1.23)	1.11 (1.09, 1.13)	<0.001
<High school	Referent	Referent	
High school diploma/GED	1.28 (1.21, 1.36)	1.14 (1.07, 1.21)	<0.001
Some college	1.47 (1.39, 1.56)	1.23 (1.16, 1.31)	<0.001
4-year degree	1.65 (1.56, 1.74)	1.32 (1.24, 1.40)	<0.001
>4-year degree	1.79 (1.69, 1.88)	1.38 (1.30, 1.46)	<0.001
Smoking status			
Never	Referent	Referent	
Former	1.10 (1.07, 1.13)	1.05 (1.02, 1.08)	0.001
Current	0.78 (0.74, 0.84)	0.93 (0.87, 0.99)	0.023

Note: This table highlights the regression results for the retention to next follow-up conditioned on having attended all previous follow-up appointments. The first column shows unadjusted relative odds (and 95% Wald-based confidence intervals) of retention for the defined race and ethnic groups and each of the adjustment variables. The second column depicts the relative odds (and 95% Wald-based confidence intervals) of retention for the race and ethnic groups after adjusting for each of the a priori specified potential confounders. The third column specifies the p-values associated with the adjusted analysis results. The adjusted estimates were based on 38,616 participants of which 7,569 were retained. Of these participants, 224 identified as AI/AN-only with 27 of them were retained.

Abbreviations: AI/AN, American Indian and Alaska Native; GED, General Educational Diploma; HW, Hispanic White; MCI, mild cognitive impairment; NHW, non-Hispanic White

[a]The "Other" race category consists of participants who identified as Native Hawaiian or Pacific Islander, unknown race, multiracial, or White participants with unknown Hispanic ethnicity.

affected AI/AN populations.[17] However, our results do not suggest a differential effect of COVID on retention between AI/AN and NHW participants. In light of how COVID impacted minoritized communities, these results may be surprising.[18,19] However, few AI/AN participants enrolled within the year and a half of COVID reaching the United States, potentially limiting the impact of the pandemic on our primary analyses.

Participant retention in longitudinal studies is critical to maintaining study power, reducing bias, and ensuring generalizability.[20] In longitudinal analyses, statistical methods require a minimum of three visits per individual to estimate patient trends over time. Thus participants with fewer than three visits are commonly excluded from analyses assessing longitudinal trends. Furthermore, if participants who are lost to follow-up differ from participants who remain in the study then selection bias is likely to result. Specifically, if participant attrition is due to a reason related to an uncollected characteristic, or for a reason related to the outcome of interest, then results from a statistical analysis may contain significant bias, even in settings with little loss to follow-up.[21]

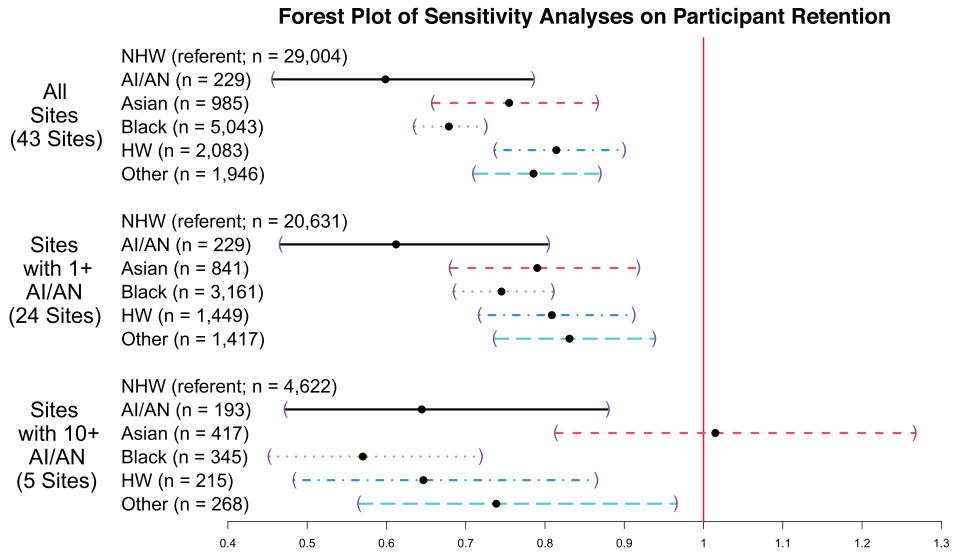


FIGURE 1 Forest plot of the odds ratios for site-specific sensitivity analyses on retention to first follow-up visit for the race and ethnicity groups compared to non-Hispanic White (NHW) participants.

Even in the absence of bias, however, the loss in power may increase the probability of type 2 error. In addition, prospective observational settings (e.g., NACC) may not generalize to the broader population from the start because the sample of participants may not be representative of the overall population. Thus differential attrition in addition to potential analytical biases may make it difficult to draw meaningful conclusions that generalize to any population.[20]

The results of our work imply that efforts to retain AI/AN study participants should be prioritized. Retention of minority participants may be improved through tactics such as including community members in study design and data collection; providing detailed information on the research goals and how participant data will be used, as well as sharing benefits of individual participation; and limiting barriers to entry and continued participation.[22–34] A recent secondary analysis by Salazar et al.[35] found that retention strategies focused on "study personnel" and "study description" were associated with greater participant retention in NACC UDS data. They did not observe effect modification by race and ethnicity. The "study personnel" strategy included tactics such as diverse staff, regular retention trainings for staff, and continuity between specific staff members and specific participants over time.[35]

Within the NACC UDS, we previously observed a positive association between the number of retention tactics employed by a site and the rate of participant retention.[12] Under the possibility of site-specific retention practices being different between sites with AI/AN participants and those without AI/AN participants, we repeated our primary analyses on two subsets of the sites: (1) all sites with at least one AI/AN participant and (2) all sites with at least 10 AI/AN participants. In both settings, our analyses resulted in nearly identical odds ratios for retention between AI/AN and NHW participants. The results of Salazar et al. also suggested that any differences in retention strategies between the sites did not differentially impact the relative odds of attrition between AI/AN participants and NHW participants.[35] However, we observed lower retention rates for Black and HW participants for sites with at least 10 AI/AN participants, compared to the analysis with all sites. This suggests that there may be differences in retention among some racial and ethnic groups, but those differences are not observed between AI/AN and NHW participants. Our data do not inform whether these differences could be related to differences in site-specific retention practices or if similar tactics may have differentially affected race and ethnicity groups.

When conducting research with participants from underrepresented communities it is important to take precautions to ensure all research methods, results, and interpretations are appropriate. For example, it is necessary to be aware of history of research in those communities.[36,37] Work by the Native American Center for Excellence (NACE) describes how the trust of AI/AN communities has been betrayed by researchers whose work was unethical, drew inappropriate conclusions, and was culturally inconsiderate.[38] To gain trust in Native American communities, NACE recommended that researchers work with communities as partners.[38] For example, previous work has suggested developing a sense of community/research partnerships by regularly providing research feedback to participants (and the community), offering small personal items with the study logo, and hiring community members as part of the team.[25,29,31,33,39–41] The latter can help ensure culturally appropriate methods, reduce cultural misunderstandings, and provide participants with a trusted point of contact.[38,42] Redwood et al. also described persistence and detailed tracking of contact attempts as vital to their retention of AI/AN participants.[39]

It is worth noting that most of the studies that have considered retention in AI/AN populations are more than a decade old. The results of the present work suggest that retention gaps have persisted. It will likely be essential for researchers to actively invest time into building personal relationships in the AI/AN community to improve these outcomes. This will necessitate building enduring relationships, beyond conventional funding cycles; incorporating research strategies with long-term relationships in mind; and developing educational

programs to familiarize communities with goals and procedures. Education and relationship-building may improve community attitudes toward research over time, which directly affect willingness to participate and even study retention.[43] Investigators, not just members of the research team but lead principal investigators, can and should work directly with communities to introduce research topics, explain results, and generally educate on research practice and findings. Specific to ADRD, Jernigan et al. noted the need for education on risk factors and caretaking skills within AI/AN communities.[44] Regular presentations on ADRD topics and hosting small gatherings in which investigators invest time and energy to learn the names of local leaders and cultural traditions of the community all can help to build a relationship beyond the traditional researcher–participant interaction.

There are several limitations to our study. We aimed to assess retention of AI/AN participants in ADRCs across the United States. These results may not generalize to the overall U.S. population, to the general AI/AN population, or to other studies. For example, we observed a smoking rate of 11% among AI/AN participants, which is lower than the 27% estimated by the Centers for Disease and Prevention (CDC) report on tobacco use among AI/AN adults.[45] Furthermore, we were unable to account for differences in retention strategies employed at centers more likely to have participants of a certain race or ethnicity. In addition, we were limited to the definitions of some covariates. For example, we could not explore the intersection between sex and gender with race and ethnicity due to the wording of the data-collection instruments. Nevertheless, our work highlights an important area of deficit for ADRCs with respect to the retention of AI/AN participants. Future work can examine the time-to-return for follow-up, as well as attempt to understand how different retention tactics work with the AI/AN participants specifically, in NACC and other studies.

In conclusion, to reduce bias and improve validity of results, it is essential to retain participants in studies focused on longitudinal outcomes. For generalizability, identification of subgroup-specific risk factors, and ensuring health equity, it is especially important to retain participants from underrepresented populations. Participants who identify as AI/AN are vastly understudied and underrepresented, despite a disproportionate burden of disease. Our analyses of retention show that AI/AN participants were not retained at similar rates as NHW participants. To effectively learn more about ADRD in AI/AN communities, concerted efforts will be needed to increase retention of these participants.

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Acknowledgment of Data Sovereignty

As sovereign entities, tribal nations have the right to govern the collection, storage, ownership, application, and dissemination of data collected from members of their nation. Tribal nation members should, therefore, have input on the interpretation of data analyses that include American Indian and Alaska Native (AI/AN) participants to ensure respect for individuals and/or their ancestors and that the research benefits the nation. Data collection by Alzheimer's Disease Research Centers (ADRCs) consists of two parts: (1) center-specific collection protocols and (2) standardized data collection to be contributed to the National Alzheimer's Coordinating Center (NACC),[46] and includes questions about primary, secondary, and tertiary race and allows participants to self-identify their race. There are no mandatory follow-up questions on tribal affiliation. In addition, there are neither limitations to AI/AN data access nor safeguards to ensure research conducted using AI/AN data is of benefit to AI/AN communities. In the broadly available NACC data, there are no pathways to ensure that results involving AI/AN communities are interpreted correctly and disseminated to the appropriate communities. Although individual ADRCs may be working with the local AI/AN communities, there is no oversight or guidance from NACC or the National Institute on Aging to ensure and aid ADRCs in acknowledging the inherent right of data sovereignty for AI/AN communities.

We acknowledge that the present research in its current form is not directly aiding AI/AN communities. We withheld some sensitivity analyses due to the risk of loss of confidentiality among nations and peoples who have not had the opportunity to review or provide input on the current work. It is our hope that ADRCs are aware of the priorities, wishes, and goals of AI/AN participants and are working directly with the tribal nations to achieve their research goals.

For more information, please see: [47–50]

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CONFLICT OF INTEREST STATEMENT

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CONSENT STATEMENT

The present study uses wildly available data from naccdata.org and did not require informed consent. All participants and co-participants provided written informed consent before the data were collected and submitted to NACC.

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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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