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Clinical Research Participation among Aging Adults Enrolled in an Alzheimer's Disease Center Research Registry

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Abstract

In light of our limited understanding of what motivates older adults to participate in clinical studies of Alzheimer's disease (AD), the current study examines incentives and barriers to participating in AD clinical research among older adults. 235 participants enrolled in the Boston University Alzheimer's Disease Center research registry (75 ± 8 years, range 58–99 years, 60% female), a longitudinal registry from which individuals are recruited into other clinical studies, completed a survey assessing registry participation satisfaction, religiousness, trust in healthcare institutions, and medical research attitudes. Most participants reported initially enrolling in the registry for societal benefit. Insufficient time was a commonly endorsed barrier to enrolling in other Center-approved studies, particularly among younger participants. Driving and a lack of transportation to the medical facility were also barriers, particularly for older participants. Transportation was the most popular incentive, followed by home-based visits (particularly for older participants and participants with less formal education) and compensation (particularly among respondents from racial/ethnic minority groups). Participation interest in other studies was associated with favorable medical research attitudes ($r = 0.34$, $p = 0.00003$) but not religiousness ($r = -0.09$, $p = 0.21$) or trust in healthcare institutions ($r = 0.09$, $p = 0.17$). Among older adults, societal benefit is a motivating factor for registry enrollment; however, participation in additional studies is hindered by insufficient time among younger participants and transportation barriers among older participants. Providing transportation, home-based visits, and modest compensation may improve participation rates. Furthermore, favorable attitudes toward medical research are strongly associated with interest in enrolling in additional studies and may serve as a beneficial outreach triage technique.

Keywords

Alzheimer's disease; barriers; clinical research; incentives; participation

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INTRODUCTION

As many as 5.3 million Americans may have Alzheimer's disease (AD), which accounts for 60 to 80% of all dementia cases [1]. In the absence of effective prevention or treatment approaches, by 2050 the number of individuals over the age of 65 years who are affected by AD will exceed 13 million [2]. Therefore, research to advance prevention, diagnosis, and treatment is critically important.

In 1984, in response to the public health need to better understand AD, the US Congress directed the National Institutes of Health (NIH) to foster the advancement of AD research. Since that time, the NIH has funded Alzheimer's Disease Centers (ADCs) at academic medical centers throughout the US [3]. These ADCs were designed to enhance progressive AD research in medical, behavioral, and clinical science and to provide investigators with clinically characterized older adults, tissue specimens, and basic resources to facilitate innovative AD research.

One example of the ADC model is the Boston University Alzheimer's Disease Center (BU ADC), which was established in 1996. The BU ADC includes a longitudinal registry of approximately 450 older adult participants with and without memory problems who take part in annual comprehensive medical evaluations for clinical characterization [4, 5]. To facilitate scientific advances in AD, BU ADC registry participants are recruited into other Center-approved studies.

To maintain adequate registry participant volume, effective outreach and recruitment strategies are a major priority and must be guided by a critical understanding of two main elements. First, it is important to know which factors account for older adults' initial enrollment in a research registry. Recent survey data suggests older adults participate in research registries because of personal gain (i.e., to receive information about events and activities, to learn about research findings, and for social interaction) and altruism (i.e., to contribute to society and research) [6]. Second, it is important to understand why participants who are already part of a research registry either accept or decline participation in Center-approved studies. Unfortunately, there is a major knowledge gap focusing on why older adults, who are engaged enough to enroll in a research registry, participate in further opportunities. The broader literature suggests adults, regardless of medical diagnosis, are generally motivated to participate in research studies for personal [6–9] and societal benefit [6–8, 10–12]; however, it is not well known what factors predict high levels of participation among older adults once they are enrolled in a research registry.

In addition to understanding motivating factors for research participation, it is similarly important to understand why older adults do not participate in research studies and factors that minimize enthusiasm for research participation. Focus group findings from AD caregivers suggest that a lack of direct medical benefit, testing procedures, insufficient time, research skepticism, and difficulty coping with the AD diagnosis are major participation obstacles [13]. Survey and interview data suggest similar barriers are expressed in broader clinical research areas, such as cancer and diabetes trials, including caregiver unwillingness [14, 15], discomfort with research methods [10, 16], insufficient time [15, 16], inadequate transportation [15], and patients' deteriorating health [14, 15].

To better understand factors that contribute to participation in a research registry and subsequent enrollment in affiliated studies, we analyzed data from 235 BU ADC registry participants who independently completed surveys regarding their perceptions of the BU ADC research registry study and reasons for participating or not participating in other BU

ADC-approved studies. Our study had three objectives. First, we aimed to describe participants' knowledge of the registry's goals and reasons why participants enrolled in the registry. Much of the literature on older adults and clinical research participation provides evidence about recruitment strategies without first formally assessing the barriers. Therefore, our second aim sought to describe barriers and incentives to enrolling in additional studies supported by the BU ADC and assess participant characteristics associated with these barriers, including age, race, education, cognitive status, personal familiarity with AD (i.e., the respondent personally knew someone with AD), and an occupational history in science or medicine. Finally, we aimed to better understand how demographic factors, religiousness, trust in healthcare institutions, and attitudes toward medical research were related to enthusiasm regarding research participation, as some participants enroll in many BU ADC-affiliated studies (i.e., "high levels of research interest") while others consistently decline such participation. Understanding this discrepancy would aid outreach and recruitment methods by identifying factors associated with increased participation rates and improved retention strategies. We hypothesized that higher rates of research enthusiasm (i.e., expressing an interest in learning more about Center-approved studies) would be associated with higher levels of education [8, 17], the presence of a personal connection with AD [18], and more positive attitudes toward medical research [12, 19].

METHODS

Participants

As previously described [20], respondents for this survey study were prospectively recruited from the BU ADC participant registry. Briefly, the research registry is a longitudinal research program that follows older adults annually with a medical history intake with the participant and a reliable informant, neurological and physical examinations, a comprehensive neuropsychological assessment, and a consensus team diagnosis for cognitive status [4, 5]. Diagnoses for mild cognitive impairment (MCI) and AD are based on widely accepted criteria [21, 22] and are consistent with procedures put forth by the National Alzheimer's Coordinating Center for all NIA-funded ADCs [23].

In addition to the annual registry visit, subjects are recruited to participate in Center-approved studies. With BU ADC Executive Committee approval, in cooperation with the Center's Data Management & Statistics Core, study investigators are able to recruit eligible participants from the research registry via a postal mailing with study details.

As previously reported [20], all active BU ADC registry participants were contacted via postal mail with a survey packet in June 2008 ($n = 464$). Each survey packet was assigned a participant identification number to preserve confidentiality in responses, and these packets were distributed with a cover letter from the BU ADC Director explaining the survey goals, a consent statement, the survey materials described below, and a self-addressed stamped return envelope. To increase response rates, appointment reminder phone calls for annual registry visits were used to encourage interested participants to complete the survey prior to their visit. Registry participants were also queried about the receipt and completion of their survey during their annual study visit. To increase participation rates among African Americans and participants with AD, personal phone calls were made to all African American and AD registry participants who did not return their survey within 30 days. The response rate was 60% with 280 final respondents (including 235 participant respondents and 45 study partner respondents). Descriptive statistics comparing demographic and clinical characteristics (i.e., age, sex, race, education, length of time in registry) for respondents ($n = 280$) and non-respondents ($n = 184$) have been previously reported and suggest that respondents had an average of 1.3 years more formal education and had been in the registry an average of 1.2 years longer than non-respondents [20]. For the current study,

participants were excluded if someone other than the registry participant checked the respondent category indicating they were completing the surveys on behalf of the participant (e.g., a spouse or care partner, $n = 45$). These exclusions resulted in 235 participants for the current study. The Boston University Medical Campus Institutional Review Board approved the research prior to data collection.

MEASURES

As reported previously [20], the survey mailing included several self-report instruments:

1. The *Registry Participation Satisfaction Survey* queried for basic demographic information and aspects of registry study participation, including motivation for research and registry participation experience. Occupational history in medicine or science and personal familiarity with AD (i.e., the respondent personally knew someone with AD) were queried using a yes/no force-choice response. Primary reason for joining the registry was queried by asking participants to select only one of five force-choice categories. Knowledge for registry goals was queried by asking participants to select all that apply for five predetermined options. Incentives and barriers were queried using yes/no force-choice items (e.g., “Would you be more willing to participate in BU ADC studies if they were conducted in your home?”).
2. The *Intrinsic Religiousness Motivation Scale* [24] consisted of 10-items assessing self-rated religiousness (e.g., “Nothing is as important to me as serving God as best I know how”). Scores range from 10 (low levels of religiousness) to 40 (high levels of religiousness).
3. The *Healthcare System Distrust Scale* [25] included 10-items measuring attitudes toward the healthcare system, including competence, confidentiality, honesty, and fidelity, as well as beliefs about healthcare system practices (e.g., doing blood tests) and healthcare system motives (e.g., holding costs down). Scores ranged from 10 (low levels of trust) to 50 (high levels of trust).

During the registry study annual visit that followed postal mail distribution of the survey packet, each participant was requested to complete the *Research Attitudes Questionnaire* [12, 19]. This 11-item measure assesses how favorably or unfavorably one views medical research, with each item being rated between 1 (Strongly disagree) and 5 (Strongly agree). Total scores range from 11 (unfavorable attitudes) to 55 (more favorable attitudes).

DATA ANALYSIS PLAN

Prior to analyses, pro-rated scores were calculated for the *Intrinsic Religiousness Motivation Scale* ($n = 58$ participants), the *Healthcare System Distrust Scale* ($n = 15$ participants), and the *Research Attitudes Questionnaire* ($n = 3$ participants) to account for missing responses while preserving the overall estimate of these surveys [20, 26]. Specifically, missing items were assigned a pro-rated value that equaled the mean value across the remaining responses within that specific survey.

Demographic and clinical characteristics were generated for those survey respondents who met inclusion criteria for the current analyses ($n = 235$). For the first aim of the study, frequencies were summarized for knowledge of registry goals and reasons for registry enrollment.

For the second aim of the study, frequency statistics were generated for the reported barriers and incentives (e.g., providing transportation, conducting home visits) to participation in Center-approved studies. These frequencies were first calculated for the entire sample and

then chi-square analyses were used to statistically compare categorical groups, including race (White, non-White), cognitive status (cognitively impaired, cognitively normal), personal connection to AD (yes, no), and occupational history in science (yes, no). Similarly, *t*-tests were used to assess associations with age and education.

Next, a research interest ratio was calculated by dividing the number of times a participant expressed interest in learning more about a study for which they were eligible to participate by the number of times the participant was solicited [i.e., (interested in learning more/total number of solicitations)*100]. Please note that not all participants were solicited for the exact same studies. Pearson correlation coefficients were used to relate this research interest ratio to demographic variables (i.e., age, education, length of time in registry, and distance from medical center calculated in minutes) and questionnaires assessing trust in health-care institutions, religiousness, and research attitudes. Post-hoc, Spearman correlation coefficients were used to relate the research interest ratio to each of the eleven Research Attitudes Questionnaire items to identify the most salient items for research interest.

Data were analyzed using SPSS 16.0 (Chicago, IL). Significance for all analyses was set a priori at $p < 0.05$.

RESULTS

Sample characteristics

Table 1 shows the characteristics for the survey respondents included in the current study ($n = 235$). Respondents had a mean age of 75 years (58–99 years) and included 60% women. Of the 51 non-White participants, 49 identified as African American and 2 identified as Asian. Forty-nine percent of the respondents had some form of cognitive impairment (i.e., $n = 98$ with mild cognitive impairment or $n = 18$ with a dementia diagnosis) according to the consensus conference following their most recent registry visit.

Descriptives for knowledge about registry goals

The three most commonly endorsed goals of the registry included advancing research and knowledge about AD (98%), promoting brain donation (67%), and recruitment for other Center-approved studies (50%). See Table 2 for details.

Descriptive factors associated with registry enrollment

The three most commonly endorsed reasons for registry participation included advancing research about AD (i.e., societal benefit, 56%), benefiting family, friends, or future generations (i.e., personal benefit, 21%), and personal concerns for memory (i.e., personal benefit, 13%). See Table 2 for details.

Barriers associated with participating in center-affiliated research studies

When queried for barriers to participating in additional research studies, the obstacle most frequently endorsed was insufficient time (30%, see Table 2). Individuals endorsing insufficient time as a barrier were younger (72.5 ± 7.7) than individuals not endorsing this barrier (76.3 ± 8.2 ; $t_{(220)} = 3.3$, $p = 0.01$). No additional demographic or clinical characteristics were related to insufficient time as a barrier, including race ($\chi^2 = 2.5$, $p = 0.12$), education ($t_{(220)} = -0.1$, $p = 0.95$), cognitive status ($\chi^2 = 4.7$, $p = 0.32$), personal familiarity with AD ($\chi^2 = 0.1$, $p = 0.80$), or an occupational history in science or medicine ($\chi^2 = 0.6$, $p = 0.46$).

The second most frequently endorsed barrier to participation was driving into the city (28%, see Table 2). Upon further inspection, individuals endorsing driving into the city as a barrier

were older (77.1 ± 7.0) than individuals not endorsing driving into the city as a barrier (74.5 ± 8.6 ; $t_{(220)} = -2.1, p = 0.03$), and White respondents were more likely to endorse driving into the city as a barrier (52%) than non-White respondents (2%; $\chi^2 = 18.6, p = 0.00002$). However, it is noteworthy that White respondents reported longer commutes to the medical center (45.0 ± 24.1 min) than non-White respondents (30.0 ± 14.6 min; $t_{(222)} = 4.2, p = 0.00004$). No additional demographic or clinical characteristics were related to the barrier of driving into the city, including education ($t_{(220)} = 0.2, p = 0.88$), cognitive status ($\chi^2 = 2.8, p = 0.60$), personal familiarity with AD ($\chi^2 = 1.3, p = 0.54$), or an occupational history in science or medicine ($\chi^2 = 0.48, p = 0.49$).

The third most frequently endorsed barrier to participation was a lack of transportation to the medical facility (14%, see Table 2), which was associated with age ($t_{(220)} = -3.8, p = 0.0002$). That is, individuals endorsing transportation as a barrier were older (80.2 ± 10.1) than individuals not endorsing this barrier (74.4 ± 7.6). No additional demographic or clinical characteristics were related to the barrier of driving into the city, including race ($\chi^2 = 2.9, p = 0.09$), education ($t_{(220)} = 0.81, p = 0.42$), cognitive status ($\chi^2 = 5.6, p = 0.24$), personal familiarity with AD ($\chi^2 = 0.3, p = 0.57$), or an occupational history in science or medicine ($\chi^2 = 1.6, p = 0.20$).

The fourth most frequently endorsed obstacle to participation in additional research studies was a lack of financial compensation for time (14%, see Table 2). non-White respondents endorsed lack of financial compensation as a barrier more often (28%) than White participants (10%; $\chi^2 = 10.8, p = 0.001$). No additional demographic or clinical characteristics were related to the barrier of driving into the city, including age ($t_{(220)} = 1.4, p = 0.16$), education ($t_{(220)} = -0.04, p = 0.97$), cognitive status ($\chi^2 = 6.2, p = 0.19$), personal familiarity with AD ($\chi^2 = 1.9, p = 0.39$), or an occupational history in science or medicine ($\chi^2 = 1.5, p = 0.22$).

Participation incentives for center-affiliated research studies

The incentive most frequently endorsed was providing transportation (61%, see Table 2). However, no demographic or clinical characteristics were associated with transportation as an incentive, including age ($t_{(220)} = -1.3, p = 0.20$), race ($\chi^2 = 3.4, p = 0.07$), education ($t_{(220)} = 1.8, p = 0.08$), cognitive status ($\chi^2 = 4.7, p = 0.32$), personal familiarity with AD ($\chi^2 = 1.5, p = 0.46$), or an occupational history in science or medicine ($\chi^2 = 0.0, p = 0.93$).

The second most frequently endorsed incentive was home-based visits (55%, see Table 2). Individuals endorsing home-based visits as an incentive were older (76.3 ± 8.3) than those individuals not endorsing this incentive (73.5 ± 7.7 ; $t_{(220)} = -2.5, p = 0.01$), and individuals endorsing home-based visits as an incentive had less formal education (15.7 ± 3.2) than those individuals not endorsing this incentive (16.7 ± 2.8 ; $t_{(220)} = 2.5, p = 0.01$). No additional demographic or clinical characteristics were related to home-based visits as an incentive, including race ($\chi^2 = 2.9, p = 0.09$), cognitive status ($\chi^2 = 2.0, p = 0.74$), personal familiarity with AD ($\chi^2 = 1.7, p = 0.42$), or an occupational history in science or medicine ($\chi^2 = 0.4, p = 0.52$).

The third most frequently endorsed incentive was compensation for time (50%, see Table 2). non-White respondents were more likely to endorse compensation for time as an incentive (80%) as compared to White respondents (43%; $\chi^2 = 22.0, p = 0.000003$). However, there was no between-group difference ($t_{(140)} = -1.2, p = 0.23$) for the amount of compensation suggested by White (\$ 27 ± 20 /hour) versus non-White participants (\$ 31 ± 15 /hour). Also, personal familiarity with AD was borderline associated with compensation for time as an incentive ($\chi^2 = 5.7, p = 0.06$), such that individuals without personal familiarity to AD were more likely to endorse compensation as an incentive (61%) as compared to individuals with

personal familiarity to AD (46%). No additional demographic or clinical characteristics were related to compensation of time as an incentive, including age ($t_{(220)} = 1.6, p = 0.12$), education ($t_{(220)} = -0.6, p = 0.52$), cognitive status ($\chi^2 = 2.2, p = 0.70$), or an occupational history in science or medicine ($\chi^2 = 0.6, p = 0.43$).

Factors associated with research interest

Demographic variables were not related to the research interest ratio, including age ($r = 0.02, p = 0.77$), education ($r = -0.03, p = 0.69$), years in registry ($r = -0.08, p = 0.23$), or distance from the medical center ($r = -0.02, p = 0.73$). The research interest ratio was significantly correlated with the Research Attitudes Questionnaire ($r = 0.34, p = 0.000003$) such that the higher the interest ratio, the higher the research attitudes score. The research interest ratio was not associated with religiousness ($r = -0.09, p = 0.21$) or trust in healthcare institutions ($r = 0.09, p = 0.17$). Post-hoc correlations between the research interest ratio and each of the eleven Research Attitudes Questionnaire items yielded several significant associations (see Table 3 for details).

DISCUSSION

The current study aimed to better understand factors that contribute to participation in a research registry and, more importantly, enrollment in additional studies supported by the BU ADC. Findings suggest that participants believe the primary goal of the BU ADC registry is to advance research in AD, which is consistent with why participants report originally joining the registry. That is, more participants attributed joining the registry to the societal benefit of advancing research about AD than endorsing any personal benefit as a motivator (e.g., personal concerns for memory and benefiting family, friends, or future generations). Our findings support previous literature indicating older adults are more motivated by societal versus personal benefit to participate in research. In their study of clinical research barriers among 50 adults aged 75 years or older, Marcantonio et al. [27] found that 56% of participants identified benefiting mankind (i.e., societal benefit) as the primary motivation for research participation. Similarly, results from a study on older adults in a research registry by Warburton et al. [6] indicate that benefiting society and research was the main reason to join the research registry.

Several barriers were associated with lack of participation in BU ADC studies. First, participation in additional studies sponsored by the Center is reportedly hindered by insufficient time, particularly among younger participants. Transportation, including a lack of interest in driving into the city or a lack of transportation to the medical center was also reported to be a barrier. This barrier was especially endorsed among the oldest respondents and white respondents, who reported living further away from the medical center than the non-White respondents. Last, a lack of financial compensation for time was endorsed as a participation barrier, particularly among non-White participants. Our findings are supported by research in older clinical populations (e.g., patients with diabetes or undergoing surgery) that report similar barriers, including insufficient time [15, 16], inadequate transportation [15], and an unwillingness to travel to the study location [28]. Findings from the current study extend prior work by suggesting that these barriers are an issue for increasing involvement in Center-approved studies among a cohort who has already joined the registry and committed to its annual visit.

Registry participants cited the Center providing transportation as an incentive to getting more involved in Center-sponsored studies. Home-based visits were also a reported incentive, particularly among the older participants and less formally educated participants. Among non-White participants, modest compensation (our participants suggested a mean of \$31/hour) may improve participation rates for studies sponsored by the Center, though

ethical issues should be considered when offering financial compensation for participation that exceeds standard levels of compensation (e.g., payment over \$100; for a review see Grady [29]).

Findings from the present study are consistent with prior work examining incentives to participation. Marcantonio et al. [27] found that a majority of older adults (age ≥ 75 years), who were scheduled for major surgery or at high risk of hospitalization (thus, at risk for delirium), reported that transportation and free parking were the two greatest incentives to research participation. Half of participants identified a monetary stipend as an incentive. Additional literature indicates that healthy adults in general [30], and African Americans in particular [31], cite financial compensation as a motivation for participation in research. The present study extends previous literature by examining more detailed demographic characteristics among older adults (such as education level, personal familiarity with the clinical focus of the study, and prior professional experience in medicine or science) with respect to barriers and incentives, which may enable researchers to individualize their recruitment and retention efforts based on the targeted population.

Research interest was defined as the number of times a participant expressed interest in learning more about a study while taking into account the total number of solicitations to join ADC-sponsored studies. There was no association between research interest and age, education, years in the registry, travel distance from the medical facility, religiousness, or trust in health-care institutions. We did find a significant association between research interest and attitudes toward medical research (as assessed by the Research Attitudes Questionnaire). That is, a more favorable attitude toward medical research was related to a higher interest in enrolling in clinical research studies above and beyond participation in the registry. Prior research has suggested that favorable attitudes toward medical research are related to supporting research, such as supporting the use of proxy consent for enrolling non-competent patients with AD into clinical research studies [12, 19]. Our findings extend prior research to suggest that favorable attitudes about medical research are strongly related to interest or enthusiasm for involving oneself in clinical research.

To better understand which elements of the Research Attitudes Questionnaire were most strongly related to our research enthusiasm measure (i.e., interest in additional studies), post-hoc analyses related each survey item with the research interest ratio. Findings suggest the majority of Research Attitudes Questionnaire items (i.e., 9 of 11) were significantly correlated with research interest; however, upon closer inspection, those items with the strongest associations relative to the other questionnaire items (i.e., correlation values ≥ 0.25 but ≤ 0.33 representing a small effect) appear to cluster into a series of themes that emphasize (1) trust in the research establishment (i.e., “*Medical researchers can be trusted to protect the interests of people who take part in their studies*” and “*If I volunteer for medical research, I know my personal information will be kept private and confidential*”), (2) personal responsibility to help others (i.e., “*We all have some responsibility to help others by volunteering for medical research*”), and (3) research optimism (i.e., “*I have a positive view about medical research in general*”). The significant associations between specific items on the Research Attitudes Questionnaire and enthusiasm for increasing involvement in clinical research opportunities may have relevance to outreach and recruitment efforts for ADCs or other research programs recruiting older adults into clinical studies. Specifically, using a select number of items within the survey, such as those items reported here to have the strongest associations with research interest, may be valuable in screening efforts to identify older adults with the highest enthusiasm for getting involved in research. Such pre-screening could have implications for increasing enrollment numbers and minimizing attrition rates, though such implications are yet to be determined. Items from the Research Attitudes Questionnaire could also be used to assess enthusiasm among

participants already enrolled in research registries, such as those seen at NIA-funded ADCs, who have not participated in Center-sponsored studies. Participants with low research enthusiasm may be targeted for outreach strategies to decrease barriers to participation, such as providing information at appropriate levels of literacy to ensure accessibility [32]. If individuals with low levels of research enthusiasm are members of underrepresented groups, Centers may increase participation by hiring representative staff [32], having images of individuals from underrepresented communities included in educational materials [32], creating partnerships with the community [33], and developing educational and social opportunities that foster relationships that decrease mistrust [33]. Future studies should address whether survey items discussed above could be successful in an applied setting.

The present study has a number of strengths, including the high survey response rate (i.e., 60%), the comprehensive survey measures that were selected a priori based on theoretical considerations, and the combination of descriptive and quantitative data collected. Though the use of a self-administered, anonymous, mailed survey was appropriate methodology for our research purposes, a few important limitations should be considered when interpreting the results, including drawbacks inherent to survey research. That is, the self-report nature of data collection in which there is no opportunity for follow-up questioning (as opposed to individual survey administration) may have limited information provided and some questions may have presented ambiguity, making them difficult for participants to understand and respond, particularly among those respondents with clinically relevant cognitive impairment (i.e., nearly half of the sample had a diagnosis of mild cognitive impairment or AD). Second, descriptive comparisons suggest survey respondents were more educated and had spent more time in the registry as compared to non-respondents. This difference, coupled with our focus on older adults and the fact that our study was conducted at a single-site within an urban-based medical center, may limit the generalizability of our findings. Third, multiple comparisons were made, which may have yielded one or more false positive findings. Last, we defined research interest in this study as the number of times a participant expressed interest in learning more about a study while taking into account the total number of solicitations to join ADC-sponsored studies. However, it is essential to point out that research participation enthusiasm can be specific to the research study topic, such that some individuals might be willing to learn more about a low-risk study as compared to a high risk study. Therefore, the method by which we defined research interest in this study should be refined in prospective studies on this subject.

While the current study extended the literature by examining more detailed participant characteristics, such as education, personal familiarity with AD, and prior professional experience in medicine or science in relation to participation, future research is necessary to gain a more in-depth understanding of participant characteristics and attitudes that affect research participation. As an example, the extent to which one's social networks (i.e., family or friends) are involved in clinical research endeavors may increase participation enthusiasm for a couple of reasons. First, their research participation could be a community activity aimed at increasing knowledge about AD, which could be shared with their networks. Second, participants may be able to collectively address barriers to research (e.g., culturally insensitive practices) more easily as a group than as individuals working independently. Qualitative studies may be particularly useful for this purpose and include focus groups with underrepresented groups to further explore how research attitudes are formed (e.g., generational mistrust of research institutions) and ways that conversations within social networks can shift unfavorable attitudes and garner enthusiasm. Within the BU ADC, we have conducted focus groups to assess barriers and incentives to clinical research participation, as well as methods to facilitate discussion about research involvement within social networks. Based on focus group input, we are implementing and evaluating a culturally-relevant educational intervention with African American participants and their

loved ones. This intervention is led by a racial/ethnic minority staff member, who facilitates a discussion focused on mistrust as a barrier to research, benefits of research to the population in general and Black communities in particular, facts about AD, opportunities to ask questions about the disease, and information on Center-sponsored research studies. In addition to focus groups, researchers may conduct case studies of Centers and their relationships and practices with underrepresented groups (e.g., racial/ethnic minorities, rural populations) to create site-specific interventions to increase participation and improve relationships within communities. Future research efforts should also further explore the utility of the Research Attitudes Questionnaire in identifying older adults with high levels of research enthusiasm who have favorable views toward medical research. Such identification could make more effective use of resources associated with following participants in registries who are not interested in increasing their involvement to other studies and will likely minimize attrition in longitudinal studies requiring a larger commitment on the part of the participant.

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Table 1

Sample characteristics

	<i>n</i> = 235
Age, years	75.3 ± 8.1
Education, years	16.2 ± 3.0
Gender, % female	60
Race, % White*	78
Cognitive impairment, % yes	49
Registry participation length, years	5.0 ± 1.7
Personal familiarity with AD, % yes	69
Medical/scientific occupational history, % yes	39
Registry research interest, ratio	51.5 ± 23.4
Intrinsic Religiousness Motivation Scale, total score	23.6 ± 7.1
Healthcare System Distrust, total score	34.2 ± 5.2
Research Attitudes Questionnaire, total score	44.1 ± 4.5

Note. Data presented as M ± SD or percentage;

* = of the *n* = 51 non-White participants, 49 identified as Black or African American and 2 identified as Asian; cognitive impairment includes mild cognitive impairment and dementia diagnoses according to most recent registry visit consensus conference.

Table 2

Knowledge of registry goals, motivating factors for registry enrollment, & registry incentives/barriers to participation in ADC-sponsored studies

	%
Knowledge of registry goals (check all that apply)	
To advance AD research and knowledge	98
To promote brain donation among older adults	67
To provide registry for recruitment into other studies	50
To promote caregiver research and knowledge	43
To encourage African American/urban community research participation	33
Primary reason for registry participation (select only one)	
Advance AD research	56
Benefit family, friends, or future generations	21
Personal memory concerns	13
Learn more about AD	5
Enjoy spending time with staff	1
Participation barriers (yes, no)	
Lack of time	30
Lack of transportation	14
Travel into the city required	28
Lack of compensation for time	14
Memory testing	5
Participation incentives (yes, no)	
Transportation provided	61
Home-based visits	55
Compensation for time	50

Note. Data presented as percentage endorsing item.

Table 3

Research Attitudes Questionnaire item correlations with ADC research interest ratio

	M ± SD	Research interest
1. I have a positive view about medical research in general	4.7 ± 0.6	<i>r</i> = 0.25 <i>p</i> = 0.001
2. Medical researchers are mainly motivated by personal gain *	2.0 ± 1.0	<i>r</i> = -0.16 <i>p</i> = 0.03
3. Medical researchers can be trusted to protect the interest of people who take part in their studies	4.0 ± 0.9	<i>r</i> = 0.25 <i>p</i> = 0.001
4. We all have some responsibility to help others by volunteering for medical research	4.3 ± 0.7	<i>r</i> = 0.27 <i>p</i> = 0.0003
5. Modern science does more harm than good*	1.6 ± 0.9	<i>r</i> = -0.23 <i>p</i> = 0.002
6. Society needs to devote more resources to medical research	4.2 ± 0.9	<i>r</i> = 0.16 <i>p</i> = 0.03
7. Medical research needs to be closely regulated in order to prevent harm to research participants*	4.0 ± 0.9	<i>r</i> = -0.07 <i>p</i> = 0.33
8. Participating in medical research is generally safe	4.2 ± 0.6	<i>r</i> = 0.18 <i>p</i> = 0.01
9. If I volunteer for medical research, I know my personal information will be kept private and confidential	4.3 ± 0.6	<i>r</i> = 0.33 <i>p</i> = 0.000005
10. A lot of emphasis on medical research and scientific progress is likely to harm research volunteers*	1.8 ± 0.8	<i>r</i> = -0.17 <i>p</i> = 0.03
11. Medical research will find cures for many major diseases during my lifetime	3.9 ± 0.9	<i>r</i> = 0.12 <i>p</i> = 0.12

Note. M = mean, SD = standard deviation; Research Attitudes Questionnaire item range is 1–5 with higher values indicating stronger agreement;

* = denotes items which were recoded due to reverse scoring to allow for the summary score presented in Table 1; however, recoding was not applied to data presented in this table.