Published in final edited form as:

Alzheimer Dis Assoc Disord. 2010 ; 24(3): 234–241. doi:10.1097/WAD.0b013e3181c1ee01.

Recruitment of a Community-Based Cohort for Research on Diversity and Risk of Dementia

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Abstract

We describe the history, development, and success of the recruitment and screening procedures used by researchers at the University of California, Davis Alzheimer's Disease Center (UCD ADC) to facilitate minority enrollment in research. After an initial, unsuccessful approach with satellite clinics in minority neighborhoods, the ADC shifted to an active community outreach approach. Multiple strategies were implemented to remove barriers to research participation such as providing transportation to clinical appointments and offering in-home cognitive screening. Considerable resources were directed towards hiring and training bicultural and bilingual individuals with knowledge of the target populations, both as recruiters and staff involved in clinical assessment. Implementation of these methods resulted in a dramatic increase in the number of ethnic minorities enrolled (and retained) in research protocols, including protocols that are complex and longitudinal. Diversity was achieved on other variables as well; years of education in the cohort ranges from 0 – 21, with 26% having 8 years or less. The community screen identified candidates for an in depth clinical evaluation and enrollment in longitudinal research, and we examined factors that predicted a positive response to invitation for the clinical evaluation. Individuals with a broader fund of knowledge were more likely to participate independent of other variables including ethnicity and education. When diversity is an important goal active outreach is far more efficacious than clinic-based and advertising-based approaches to recruitment.

Keywords

minority recruitment; minority enrollment; bilingual; bicultural; community screen; longitudinal

INTRODUCTION

Background

The National Institutes of Health (NIH) Revitalization Act in 1993 mandated more inclusiveness in government-funded research to counter a documented lack of an emphasis on women and minorities in various aspects of clinical and biomedical research^{1,2}. Difficulty recruiting and retaining older persons of ethnic minority heritage contributes to their underrepresentation in research and requires specific, targeted strategies to alleviate this problem³. A commonly reported barrier to recruiting ethnic minorities, one that continues today, is mistrust of researchers and the medical system^{4–12}. Lack of translated materials and bilingual/bicultural staff can also be substantial barriers for those who are not fluent in English^{13,7}. Each culture and community has unique barriers and concerns regarding issues of stigma and burden

relating to aging and dementia¹⁴. This is also true for Alzheimer's disease (AD) therapeutic research trials where barriers to cultural diversity include restrictive thresholds for acceptable co-morbid medical conditions, language exclusions, educational or literacy requirements, and socioeconomic factors such as insurance status¹⁵.

A number of strategies for increasing minority recruitment in clinical and biomedical research^{4,6,16,17}, and research on AD^{11,13,18–21} have been developed. Some²² used a multi-faceted approach that builds on existing relationships within the community and utilizes the expertise of an outreach worker with strong community ties. Several investigators have reported the need for extensive outreach efforts into targeted communities^{16,18,23,24}. Cultural adaptations such as ethnic matching of research staff and participants also have been recommended^{12,18,25}.

The aims of the current paper are two-fold. First, methods used to successfully recruit a diverse cohort of older adults into the UCD ADC are described, including community outreach and screening methods. Our success was facilitated by a multifaceted strategy to establish an active outreach program and to proactively reduce key barriers to research participation among African American and Hispanic older adults. The second aim is to identify variables that predicted whether or not older adults identified in a community-based screen would complete a comprehensive, research quality clinical evaluation as prerequisite for enrollment in a longitudinal research cohort. Our expectation was that demographic variables and/or cognitive status would impact enrollment.

METHODS

Research infrastructure

The UCD ADC is comprised of two physically separate clinical sites working in coordinated fashion. Although separated by nearly 80 miles, these two sites have – through extensive shared development and quality control procedures – identical clinical and evaluation procedures.

Local environment

The major counties served by the two UCD ADC sites are Alameda, Contra Costa, Sacramento, San Joaquin, Solano, and Yolo County. Percentages of older African American, Hispanic, and Caucasian adults in each county, derived from census statistics, are presented in Table 1. The census data provides a sense of the diversity in the area served by the ADC. As shown in Table 1, the overall percentage of Hispanic individuals 60 years of age and older residing in counties in the UCD ADC catchment area ranged from 7.1% to 14.3%, with highest percentages residing in San Joaquin County and Yolo County. The overall percentage of African Americans was more variable, ranging from 1.6% (Yolo) to 14.5% (Alameda). The longitudinal cohort developed by the UCD ADC was not a statistical sampling of the local population, but the goal of the recruitment strategy was to develop a cohort that reflected the diverse racial, ethnic, and socioeconomic composition of the region.

Development of current outreach methods

In concert with the NIH mandate, investigators at the UCD ADC initiated procedures in 1992 aimed at increasing minority representation in their research program. In order to increase ethnic minority recruitment, the UCD ADC established two satellite clinics in health care settings serving large numbers of ethnic minorities, similar to other academic research centers working to increase the diversity of research participants¹⁹. The use of satellite clinics met with limited success in recruitment of minorities for longitudinal research. Reasons why the satellite clinics failed as recruitment vehicles were numerous and varied, starting with the fact that patients presenting to these clinics were seeking clinical care rather than research involvement.

In addition, the cases tended to be complicated by multiple co-morbidities. Also, patients often were poor and their social supports overloaded by multiple, major demands. For many, reaching the hospital for a single visit was a difficult logistical task. In many cases there were problems contacting individuals for yearly follow-up evaluations. Non-English speaking patients of numerous native languages used the clinics. Guiding patients through the evaluation process and providing education and support to patients and their families consumed substantial research resources. Although some referrals from the satellite clinics were recruited into the ADC, typically these individuals were fairly demented and not appropriate candidates for longitudinal research.

In 2001 the UCD ADC changed its approach, eliminating the referral-based satellite clinics and relying instead on community-based recruitment methods that emphasized more active, face-to-face screening at community events and locales, including primary care clinics. The new approach (i.e. community outreach program) was in response to limited success of the satellite clinics in comparison with other UCD ADC-associated studies, particularly the Sacramento Area Latino Study of Aging (SALSA)²⁶ and the Spanish-English Neuropsychological Assessment Scales (SENAS)^{27,28} in enrolling ethnic minority participants through the use of community-based, epidemiological recruitment methods. The transition in recruitment approach was facilitated by an NIA supplement to the UCD ADC to expand minority recruitment. The new recruitment goals were ambitious but focused: (a) creating a cognitively heterogeneous sample for longitudinal follow-up that was 1/3 Hispanic, 1/3 African American, and 1/3 non-Hispanic Caucasian, (b) enhancing the sample so that the widest variability possible in educational achievement was obtained, and (c) achieving a spectrum of cognitive function from normal to mildly impaired to demented in response to the scientific aims of the UCD ADC that sought to understand risk factors that influence onset and trajectories of cognitive impairment. These goals were based on substantial scientific evidence that social economic status, use of a second language, educational achievement and vascular risk factors may be important modifiers of cognitive health

Substantial resources were devoted to this outreach strategy. Initially, these resources came support through the NIA ADCC (P30 AG10129, Charles DeCarli, PI) and a R01 that stressed minority recruitment (R01 AG010220, English and Spanish Assessment of Cognition in the Elderly; Dan Mungas, PI). Initial success of our recruitment efforts combined with refunding of a R01 that stressed minority recruitment (R01 AG010220, English and Spanish Assessment of Cognition in the Elderly; Dan Mungas, PI), enabled further recruitment and subsequent additional grant funding to support ongoing recruitment and retention. Four full-time employee positions were created and filled by bicultural/bilingual African American and Hispanic recruiters. These were in addition to other bicultural and bilingual staff hired shortly before or during the development of this community based cohort. The new outreach strategy included educational presentations at churches, senior centers, and support groups where research opportunities within the UCD ADC were described; circulating educational and research information at health fairs; distributing recruitment flyers to contacts within the community; and following up word-of-mouth referrals from actively enrolled participants who recruited others (i.e., family members and friends) to the research. Recruiters created their own lists of individuals and organizations to approach about research projects within the ADC based on their knowledge of the target communities and relationships established with various entities within the communities. Although different recruiters used somewhat different methods, a common feature was that considerable time (i.e., multiple extended visits over weeks or months) was spent at promising sites. Of particular note, word-of-mouth referrals proved to be a very effective recruitment technique. When not actively recruiting new participants, recruiters were directly involved with follow-up clinical evaluations and other research procedures (e.g., neuropsychological testing, blood draws) of participants they initially recruited to the research program to assure continuity between the ADC and the community-based recruitment. It should

be noted that outreach recruitment was not restricted to individuals of ethnic minority heritage. Repeated evaluation of progress and updates in recruitment strategies were made to provide balance across ethnic groups by recruiting sufficient numbers of Caucasian older adults from similar places.

Other strategies used to reduce barriers to participation included in-home visits to administer cognitive testing and other procedures. In addition, collateral source data was collected by telephone from informants who were not available to drive or accompany the participant to research visits. Spanish-language neuropsychological testing materials and consent forms were provided for Spanish speaking individuals. Dedicated UCD ADC drivers transported participants to UCD ADC clinics in Martinez or Sacramento for the clinical exam and imaging. Participants who provided their own transportation were compensated for doing so. Research budgets paid for research magnetic resonance image (MRI) scans for all participants who could be scanned, although an MRI scan was not an inclusion criterion. Participants were paid a stipend for participation, including a lunch stipend. Continued contact between participants and the recruiter responsible for the original identification and screening was encouraged, and involved helping with scheduling appointments, data collection, accompanying participants to brain imaging, and often providing feedback about the clinical evaluation.

Eligibility screening

The outreach nature of the new recruitment strategy led to the implementation of a multi-step process to ensure enrollment of appropriate participants. First, initial eligibility was determined based on criteria broadly including that a given individual was aged 60 or older, of a target ethnic group, and fluent in English or Spanish. Second, individuals who met these criteria were administered a subset of the SENAS^{27,28} that required one to two hours to complete. Third, these SENAS results were then used to identify candidates for a clinical evaluation and possible entry into the longitudinal cohort. Goals for selection were to obtain a broad range of cognitive function from normal to demented, with a particular emphasis on mild cognitive impairment. To achieve these goals, all individuals with significant impairment on any one of five SENAS scales measuring episodic memory, language/semantic memory, spatial ability, abstract reasoning, and attention span were identified as potential candidates. Significant impairment was defined as an age-, education-, and language-adjusted SENAS score below the 10th percentile. In addition, a 25% random sample of screened individuals with no significant impairment on these five measures was identified. (Weighted sampling based on test scores was not an effort to establish prevalence rates for MCI or dementia but rather was a recruitment stratification tool used to obtain a cognitively diverse sample.) Fourth, medical history of individuals identified as potential recruits was then reviewed to screen out those who met exclusion criteria that included unstable major medical illness, major primary psychiatric disorder (history of schizophrenia, bipolar disorder, or recurrent major depression), and substance abuse or dependence in the last five years. These criteria are consistent with other research protocols within the UCD ADC. Based on these steps, eligibility for a clinical evaluation was established. Finally, enrollment in longitudinal research was offered to those who completed the clinical evaluation and continued to meet study eligibility criteria. All participants signed informed consent.

Clinical evaluation and research MRI

The clinical evaluation consisted of a medical history, physical, and neurological exam, neuropsychological assessment, research MRI scan, and a multi-disciplinary consensus diagnosis determined in the ADC case adjudication process. All participants received full dementia work-ups, and were diagnosed according to methods used for all ADC patients. Standardized MRI scans were obtained on all participants who consented to a scan and did not have MRI exclusions (e.g., pacemaker, metal implants). MRI was not a requirement for

inclusion in the longitudinal cohort, although 86% of those subsequently enrolled did complete a MRI scan. For cognitively impaired individuals who could not complete a MRI scan a clinical computed tomography (CT) scan was ordered as part of the standard diagnostic work-up.

Neuropsychological test battery

The SENAS consists of psychometrically matched scales, both within and across English and Spanish language versions, constructed using item response theory (IRT) methods. The goal of scale development was to provide unbiased assessment of cognitive abilities across ethnic and linguistic groups. Abilities assessed by the neuropsychological scales include conceptual thinking, semantic memory, attention span, episodic memory, spatial ability, verbal ability, and executive function. SENAS scores derived for each participant from a subset of the neuropsychological scales were used, as previously described, to classify participants as normal or cognitively impaired for the purpose of further recruitment. These scales, which were used in the current paper to predict likelihood of completing a clinical exam, measured object naming, pattern recognition, verbal episodic memory, verbal attention, and verbal abstraction.

Statistical analysis

Much of the literature on recruitment and retention of ethnic minorities in research is qualitative²⁰. In the current paper, in addition to describing strategies used to bolster diversity in our longitudinal cohort, we provide quantitative information about variables that related to success in our recruitment effort to obtain clinical evaluation as a prelude to enrollment in longitudinal research. To that end, logistic regression was used to determine whether or not differential recruitment occurred across groups and as a function of demographic and cognitive variables. The modeling process consisted of first examining single demographic variables (i.e., age, education, ethnicity, and gender) and SENAS scores as predictors of the odds of completing a clinical evaluation in univariate logistic regression models. Significant, individual predictors from the univariate models then were combined in multivariate models (e.g., ethnicity and education) and the likelihood of completing an evaluation was again modeled. Ninety-five percent confidence intervals were calculated for all odds ratios. Significance levels for all tests were set at level .05.

RESULTS

Sample description

One goal of the community outreach recruitment strategy was to obtain the widest variability possible among recruits to the longitudinal cohort in terms of demographic characteristics such as age, ethnicity, and educational attainment. Table 2 highlights changes in participant characteristics before and after the adoption of our current approach to recruitment and shows the considerable overall increase in diversity obtained for the longitudinal sample with the implementation of the community outreach recruitment program. During the period from 1996 to 2001, 71 older persons of ethnic minority heritage were enrolled in the longitudinal research cohort. From 2002 to 2007 291 older adults from ethnic minority groups were enrolled into the cohort, a four-fold increase.

Table 3 shows demographic characteristics of Caucasian, African American, and Hispanic older persons recruited through the UCD ADC community outreach program (2002–2007) in terms of numbers of individuals who: (a) completed a cognitive screen, (b) were referred for a clinical evaluation, and (c) completed the clinical evaluation as a prerequisite for enrollment into the longitudinal cohort. Within each category of community recruit, there were significant differences in education ($p < 0.001$). Hispanic older persons had substantially less education (6 to 7 years on average) than African Americans (13 years) and Caucasians (14 years). There were significant but smaller differences in age within each category of community recruit (p

< 0.001). Among those who completed the SENAS and those referred for a clinical evaluation, Hispanic individuals were two to three years younger on average than all other groups.

Another goal of the new recruitment strategy was to develop a sample that included wide demographic diversity; in particular, we targeted a broad range of educational attainment. Table 4 shows educational attainment for African American, Hispanic, and Caucasian older adults recruited into the longitudinal research cohort as a function of age. The top half of Table 4 shows education by age obtained in the community-based longitudinal research cohort. The bottom half of the table presents summary statistics from 2000 census estimates for the six-county area served by the UCD ADC. Individuals from all ethnic groups were recruited into the sample with levels of formal education ranging from 0 to 21 years, and there was good representation across levels of education for most age groups. Although there was general agreement with census statistics, some differences emerged. For African American older adults, percentages with college education were higher for most age groups, and proportionally fewer achieved less than a high school education. In contrast, for Hispanic older persons, individuals with high school or less tended to be overrepresented in comparison with census data.

Participant flow

A flowchart detailing the outcome of community screening by the UCD ADC is presented in Figure 1. As of October 2008, 1357 older adults of diverse ethnic heritage completed cognitive screening with the SENAS. Based on SENAS scores obtained by the 1357 individuals, 661 were referred for a clinical evaluation (231 African Americans, 240 Hispanics, 165 Caucasians, and 25 persons from other ethnic groups). Of those referred for clinical evaluation, 404 completed the evaluation (145 African Americans, 124 Hispanics, 120 Caucasians, and 15 persons from other groups), with group completion rates of 63%, 52%, 73%, and 60%, respectively. Because a primary goal of the screening process was to assemble a longitudinal cohort that roughly matched the distribution cognitive impairment in the community, the vast majority of those referred for clinical evaluation were either cognitively normal or had mild cognitive impairment and relatively few had dementia. Since the number of older adults of 'other' ethnic minority heritage was too few to analyze, their data will not be discussed further. Of the older adults who completed the clinical evaluation, 301 or 75% were enrolled in the longitudinal cohort, including 131 African Americans, 92 Hispanics, and 78 Caucasians. There are a number of reasons that approximately 25% of subjects who completed the clinical evaluation were not enrolled in the longitudinal study. The most common reason was the need to balance the cohort in terms of diagnosis (i.e. normal, MCI, demented), ethnicity, age, and education. Other reasons for not enrolling include that exclusionary factors were discovered in the course of evaluation, and difficulties getting the participant through the clinical work up indicated low likelihood of continued participation. .

Predictors of clinical evaluation completion rates

Univariate nominal logistic regression modeling was used to identify demographic and cognitive variables that predicted the likelihood that those referred for clinical evaluation would complete the evaluation. Of the demographic variables analyzed, both ethnicity and education predicted odds of completing the clinical evaluation ($ps < 0.001$), but age and gender did not ($ps > 0.17$). African American and Hispanic older adults were 0.63 (95% confidence interval [CI] 0.41 – 0.98) and 0.40 (0.26 – 0.61) times as likely as Caucasian older adults to complete the clinical evaluation, respectively. Moreover, Hispanic older adults were 0.63 (0.44 – 0.92) times as likely to complete a clinical evaluation as African American older adults. Higher education was associated with completing the clinical evaluation; a one-year increase in education being associated with a 9% greater likelihood of completing a clinical evaluation (odds ratio [OR] 1.09, 1.06 – 1.13).

Next, the impact of cognitive measures on the likelihood of completing a clinical evaluation was examined based on the hypothesis that older persons who were cognitively impaired would be less likely to complete the evaluation. The overall models were significant for all five SENAS variables and showed that individuals with better object naming (OR for a one s.d. higher score = 1.58, 1.35 – 1.86, $p < 0.001$), pattern recognition (1.35, 1.15 – 1.61, $p = 0.001$), verbal memory (1.19, 1.01 – 1.40, $p = 0.03$), verbal attention (1.33, 1.15 – 1.54, $p < 0.001$), and verbal abstraction (1.49, 1.26 – 1.78, $p < 0.001$) were more likely to complete a clinical evaluation than those with poorer performance.

Finally, variables that were significant individual predictors of the likelihood of completing a clinical evaluation in univariate logistic models were examined jointly in multivariate logistic models. The joint effects of education and ethnicity were also included due to the considerable literature showing the modifying effect of education on ethnicity as it relates to cognitive performance. In this model educational attainment remained a significant predictor of the likelihood of completing a clinical evaluation after accounting for the effect of ethnicity (OR associated with one year greater education = 1.08, 1.04 – 1.13, $p = 0.001$); the effect of ethnicity, however, was no longer significant ($p = .35$). Noting the relatively strong effect of object naming performance on likelihood of completing an evaluation, the joint effect of naming and each of the other measures of cognitive performance was examined in multivariate logistic models. In each instance, object naming remained a significant predictor of the likelihood of completing a clinical evaluation ($ps < .0006$), but none of the four other cognitive variables was significantly related to likelihood of completing an evaluation independent of object naming. Also, the joint effects of ethnicity and object naming were examined; object naming remained a significant predictor of likelihood of completing an evaluation (1.47, 1.22 – 1.79, $p < 0.001$), but ethnicity was not significant ($p = 0.61$). For the final multivariate logistic regression model, the joint effects of ethnicity, education, and object naming on the likelihood of completing a clinical evaluation were examined. Object naming remained a significant predictor after accounting for the effects of ethnicity and education (1.33, 1.08 – 1.65, $p = 0.007$), education was marginally related (1.05, 1.00 – 1.10, $p = 0.03$), and ethnicity was not significant ($p = 0.79$).

DISCUSSION

Research on ethnically diverse older populations is vital if we are to fully understand the risk factors and biology of impairments in cognitive aging. Successfully including diverse populations in research often presents challenges that require innovative approaches to recruitment and retention. This article described a systematic research effort initiated by our program in 2001 to address these challenges to substantially increase the diversity of our research participants in order to achieve the goals of our clinical research program.

The community outreach program that started in 2001 resulted in successful recruitment of a very diverse longitudinal research cohort, especially with respect to ethnic minority representation and educational attainment. A major change in approach was the shift from referral-based recruitment and use of satellite facilities to active outreach and recruitment in community settings. Contacts with potential recruits involved direct solicitation via numerous venues within target communities. This kind of direct, face-to-face outreach has been shown previously to be a very successful recruitment strategy⁸. The change in strategy had important consequences. In addition to a dramatic increase in demographic diversity, the resulting cohort spanned the entire spectrum of cognitive function from normal to demented, in contrast to previous minority outreach efforts by our group that led primarily to recruitment of individuals with dementia. The broad variability of cognitive function within our longitudinal cohort is of particular value for studies that characterize the transition from normal function to dementia and identify predictors of early cognitive decline. Another consequence of our approach was

that participants from the different ethnic groups were recruited from the same or similar settings.

The strategic change to active community outreach was complemented by a constellation of strategies that focused on specific barriers to minority recruitment and enrollment identified in previous literature and in our earlier attempts. We utilized bicultural and bilingual staff, conducted evaluations in the home, and provided transportation for evaluation procedures that could not be completed in the home. In short, we actively made research participation as convenient and comfortable as possible. Our approach was multifaceted and did not permit a formal, experimental design to examine the efficacy of particular recruitment strategies. Future research to identify specific component strategies that best increase the enrollment of older persons of ethnic minority heritage is needed.

In addition to planned strategies identifying diverse participants in our research and reducing barriers to participation, there were equally important but less tangible efforts. Of greatest importance were attempts to create an environment of respect and trust for the individuals being asked to partner with us in our research program. We believe one of the most important efforts contributing to this environment was hiring recruitment and research staff of a similar ethnicity, culture, and language as those being recruited²³. Others have suggested the inclusion of bilingual, bicultural staff on research teams is critical for recruiting and retaining Hispanics/Latinos²⁹. And some³ have recommended that those who administer research protocols among older adults of ethnic minority heritage should be culturally competent with the target population. In our research program, anecdotal evidence suggests having bicultural/bilingual staff was an effective strategy for overcoming fears and distrust of researchers. During initial contacts with prospective recruits, African American recruits made references to past abuses by medical researchers, such as the Tuskegee Study. Latinos/Latinas voiced concerns and were hesitant about researchers coming into their homes and giving out personal information. However, after conversing with the recruiters and discovering they would administer the in-home testing, both African American and Hispanic recruits agreed to cognitive screening. African American participants spontaneously commented it was important that individuals familiar with their culture and ethnicity were involved with the study. That both African American and Hispanic participants frequently recommended the study to other members of their community suggests a level of trust was obtained by the research team.

The approach described here involved multiple stages and different levels of participation. Many individuals were involved only in the initial cognitive testing protocol, a separately funded project that supported the development and validation of the cognitive measures of the SENAS^{27,28}. A subset of these individuals was invited to participate in a clinical evaluation and MRI scan, and a subset of those who completed the clinical evaluation was invited into our longitudinal research cohort. These different levels of participation all made important contributions to our overall research program, but each progressive step involved increasing demands on the participants with greater commitment. This raises an important question about factors associated with willingness to increase one's commitment to research, and the design of our research program permitted studying this question with both formal and informal methods.

About 60% of those who completed cognitive testing and were recruited for a clinical evaluation subsequently completed the clinical evaluation. Qualitatively, after initial approaches, some older adults provisionally indicated an interest in participating in the research, but would end up not doing so. Reasons for this sometimes involved reservations and/or objections from adult children, including: denials that the parent had a problem, not wanting to be involved in the "back and forth" required, and concerns that participation would lead to the loss of the parent's drivers' license. Also, some potential recruits wanted to

participate in the research in anticipation of the social services available through the ADC; however, adult children would veto the decision, maintaining the family was able to take care of their own. This suggests that future strategies should include directed efforts to explain the research program to adult children, with an emphasis on differentiating normal cognitive aging from cognitive impairment.

We also were able to examine quantitative variables associated with participation in the clinical evaluation phase. This is important due to limited empirical data addressing this question. There were significant differences in participation rates across Caucasian, African American, and Hispanic older adults. But the most striking finding was that the best predictor of whether or not an individual completed a clinical evaluation was performance on an object naming task. This finding was unexpected, and indeed, our expectation was that those with greater cognitive impairment and generally more frailty would be less likely to participate. Contrary to this expectation, age was not related to likelihood of further participation, and memory performance, the best indicator of general cognitive status^{30,31}, had the weakest relationship with further participation of all of the cognitive test variables. After accounting for object naming ability, ethnicity was not independently related to participation, and education had a weak albeit statistically significant relationship.

Object naming is a component of verbal semantic knowledge acquired over the life span. While it is sensitive to diseases causing cognitive impairment, it is less sensitive than episodic memory^{30,31} and is strongly influenced by life experience including education in its broadest sense. Our results suggest that those with a greater fund of knowledge, who were, therefore, possibly more informed about science and research, were more likely to become involved in research, even after controlling for ethnic differences and differences in amount of educational achievement. However, it should be noted that many individuals with very low levels of education and with relatively lower object naming ability did agree to further research participation, which points to other factors influencing this decision, and the need for further research to better understand these factors.

Spontaneous feedback about the research program often was provided by participants and their families, and this aids understanding perceived benefits of research involvement. Many family members appreciated the information and resources provided by the ADC that would not have been obtained otherwise. Participants and family members commented on the relaxed, non-threatening environment created by the ADC staff, also described as being friendly and hospitable.

The community recruitment effort herein described was successful in meeting specific goals for our program, but would not necessarily work in all contexts. For example, this approach would be less appropriate if the overall goal was to recruit for clinical trials on Alzheimer's disease. Most recruits were not demented and inclusion criteria were quite liberal compared to the typical clinical trial situation. The challenge for investigators is to develop recruitment methods specific to their particular research needs and communities of interest, rather than implement a one-size-fits-all approach to recruitment and retention²⁵. Another important consideration is that our approach was quite effort and resource intensive. We believe development of a bicultural and bilingual staff, including general clinic staff as well as recruiters, was central to our success. Achieving this complement of staff resulted from a long-term commitment to research on diversity and to the populations of interest; and this kind of programmatic commitment may be essential for success in working with individuals from diverse backgrounds. The basic lesson of our experience is that when diversity, broadly considered, is an important goal, active outreach is far more efficacious than methods that rely on candidate participants coming to the center, as is the case in clinic-based and advertising-based approaches.

Acknowledgments

Esther Barajas-Ochoa, Gwen Gates, Cendy Carrasco, and Rochelle Williams had primary responsibility for implementing the participant recruitment protocol. Multiple staff members were involved in scheduling and conducting clinical evaluations. This research was supported from a grant from the National Institute on Aging (AG010129)

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Figure 1.
Flowchart of Outcome of Screening among Community Recruits

Ethnic Composition of Major Counties Served by the University of California, Davis Alzheimer's Disease Center (UCD ADC)

Table 1

County	Total Population	Population aged 60 and older	Percent Aged 60 and Older		
			White, not Hispanic	African American	Hispanic
Alameda	1,443,741	195,249	56.0	14.5	9.3
Contra Costa	948,816	142,932	75.0	7.0	7.5
Sacramento	1,223,499	178,183	74.5	6.6	7.1
San Joaquin	563,598	78,070	69.1	4.7	14.3
Solano	394,542	50,232	64.5	11.2	8.1
Yolo	168,660	20,748	77.9	1.6	13.8

Note. Total population data and percentage ethnic composition of each county derived from U.S. Census Bureau, Census 2000.

Table 2

Comparison of ADC participants recruited before and after the implementation of the community outreach recruitment program in 2001

	1996–2001	2002–2007
Ethnicity – N (%)		
African American	33 (7.0)	151 (24.3)
Hispanic	23 (4.9)	127 (20.5)
Caucasian	395 (84.2)	320 (51.5)
Other Minority	18 (3.9)	23 (3.7)
Education		
Mean (s.d.)	14.1 (3.5)	13.0 (4.3)
Diagnosis – N (%)		
Normal Cognition	94 (20.1)	241 (38.8)
Mild Cognitive Impairment	101 (21.5)	222 (35.8)
Dementia	274 (58.4)	158 (25.4)

Table 3
Characteristics of Community Recruits Who Completed Screening, Were Referred for Evaluation, and Completed a Clinical Evaluation

Group	Completed SENAS				Referred for Clinical Evaluation				Completed Clinical Evaluation			
	N	Female %	Age <i>M SD</i> [range]	Education <i>M SD</i> [range]	n	Female %	Age <i>M SD</i> [range]	Education <i>M SD</i> [range]	n	Female %	Age <i>M SD</i> [range]	Education <i>M SD</i> [range]
Caucasian	447	61	74 ± 8 [60 – 96]	13.9 ± 3.1 [5 – 20]	165	56	76 ± 8 [60 – 93]	13.9 ± 3.4 [6 – 20]	120	51	77 ± 8 [60 – 93]	13.9 ± 3.4 [6 – 21]
African American	424	69	73 ± 7 [60 – 91]	12.9 ± 2.8 [3 – 20]	231	69	75 ± 7 [60 – 91]	12.8 ± 3.0 [3 – 21]	145	71	75 ± 7 [60 – 91]	13.1 ± 2.9 [3 – 21]
Hispanic	427	68	71 ± 7 [60 – 94]	6.4 ± 4.7 [0 – 20]	240	66	73 ± 7 [60 – 94]	6.5 ± 4.8 [0 – 21]	124	68	73 ± 7 [60 – 90]	7.5 ± 5.2 [0 – 21]
Other	58	64	74 ± 7 [60 – 85]	12.6 ± 3.4 [4 – 19]	25	64	76 ± 7 [60 – 84]	11.5 ± 3.8 [6 – 19]	15	57	76 ± 7 [60 – 84]	12.4 ± 3.5 [7 – 19]
Total	1357				661				404			

Note. Ethnicity data missing for one participant who completed cognitive screening with the SENAS.

Table 4

Educational Attainment by Age and Ethnicity of Community Outreach Participants Successfully Recruited into Longitudinal Research Compared to Census Statistics

	UCD ADC Community-Based Cohort									
	African American			Hispanic			Caucasian			
	≤ 12	13–15	16+	≤ 12	13–15	16+	≤ 12	13–15	16+	16+
60 – 64	25.0	50.0	25.0	88.9	11.1	0.0	0.0	50.0	50.0	50.0
65 – 69	22.2	50.0	27.8	70.0	15.0	15.0	35.7	35.7	28.6	28.6
70 – 74	37.5	40.0	22.5	77.3	9.1	13.6	33.3	33.3	33.3	33.3
75 – 79	62.1	31.0	6.9	94.1	5.9	0.0	45.8	0.0	54.2	54.2
≥ 80	55.6	22.2	22.2	93.3	0.0	6.7	61.9	14.3	23.8	23.8

	Six-County Catchment Area									
	African American			Hispanic			Caucasian			
	≤ 12	13–15	16+	≤ 12	13–15	16+	≤ 12	13–15	16+	16+
60 – 64	37.2	46.7	16.2	65.8	22.9	11.3	29.1	32.8	38.1	38.1
65 – 69	45.6	37.5	17.0	72.1	19.1	8.7	36.2	31.7	32.2	32.2
70 – 74	55.3	31.4	13.4	78.7	15.8	5.5	44.8	29.7	25.5	25.5
75 – 79	66.6	18.5	14.9	82.5	11.8	5.7	48.0	28.0	24.0	24.0
≥ 80	75.2	15.4	9.3	86.3	7.8	5.9	56.3	23.3	20.4	20.4

Note. Summary statistics for six-county area served by UCD ADC derived from U. S. Census Bureau, Census 2000.