

Publications on Methods of Recruitment of Diverse Older Adults By CADC Faculty and Scientists

To eliminate health disparities and better understand aging processes in ethnically diverse populations, effective strategies for increasing participation of minority populations in health research are needed. CADC faculty and scholars have advanced these strategies in several ways through our projects recruiting patients from health care settings and recruiting individuals from communities. We summarize here our research publications on the following aspects of recruitment of diverse older adults and other health disparities populations.

- 1) Overarching issues in recruiting diverse older adults
- 2) Key determinants of successful recruitment
- 3) Innovative strategies to recruit diverse populations
- 4) Experimental studies of the effectiveness of different methods of recruitment
- 5) Feasibility of recruitment: guidelines and examples

Our guiding framework is based on our experiences conducting the research reported in all of these studies. Our aim has been to understand the many determinants of successful recruitment, and design recruitment strategies to address these. Our framework of determinants includes:

- <u>Salience of research topic or program</u>: interest in the research topic or content of intervention, cultural relevance, perceived benefits of intervention.
- <u>Study characteristics</u>: protocol, burden, location of program and/or assessments, convenience, duration, potential benefits to participants.
- <u>Exclusion criteria</u>: health conditions, age.
- <u>Characteristics of individuals being recruited</u>: limited English proficiency, experience with research, attitude about research, competing demands, health, health literacy, perceived benefit, and perceived burden.
- <u>Recruitment methods</u>: proactive (actively seeking out participants) vs passive (posting flyers), methods adapted and tailored to population, e.g., those with limited English proficiency (simplified consent process, explanations of research or randomization), method of initial contact (in-person, letter, phone call), explanations of study, complexity of messaging, cultural and language appropriateness.
- <u>Study personnel</u>: congruence of all recruiters with target population (race/ethnicity, language, culture), cultural/linguistic competence, sensitivity, interpersonal skills.
- <u>Support of others</u>: physicians or family members are supportive of participation, endorsements by physicians or key community leaders.



Overarching Issues in Recruiting Diverse Older Adults

Nápoles-Springer AM, Santoyo J, Stewart AL. Recruiting ethnically diverse general internal medicine patients for a telephone survey on physician-patient communication. *J Gen Intern Med*. 2005 May;20(5):438-43. PMCID: <u>PMC1490122</u>.

This article depicts visually a conceptual framework of determinants of participation of diverse populations. The framework is similar to our guiding framework. The figure includes recruitment determinants (sampling frame, individual factors, study characteristics, recruitment methods, and personnel characteristics), stages of participation (identify sampling frame, initial contact, establishing eligibility, initial response), and types of loss at each stage (e.g., wrong contact information, ineligible, poor health, not interested). Use of such a framework provides a foundation for planning recruitment strategies to maximize success. The paper reports on differences in recruitment by several race, ethnic, and language groups.

Nápoles AM, Chadiha LA; Resource Centers for Minority Aging Research. Advancing the science of recruitment and retention of ethnically diverse populations. *Gerontologist*. 2011 Jun;51 Suppl 1(Suppl 1):S142-6. PMCID: PMC3092974.

This is a commentary in a special issue of *The Gerontologist* entitled "The Science of Recruitment and Retention Among Ethnically Diverse Older Adults." It highlights challenges that must be addressed to advance the science of recruitment of ethnically diverse older adults and describes strategies used by the Resource Centers on Minority Aging Research. The authors recommend studies to generate evidence on successful methods of recruitment and retention.

- Track and report recruitment and retention outcomes, stratified by race/ethnicity (e.g., % contacted, % enrolled, % retained).
- Conduct nested studies of recruitment methods within larger studies.
- Create funding opportunities to incorporate nested studies of recruitment within larger studies.



Key Determinants of Successful Recruitment

Three publications explored specific determinants of successful recruitment. These explored attitudes, knowledge and willingness to participate in clinical trials of African American, Asian, and Latino men with prostate cancer (Kaplan et al., 2015), a literature review of mistrust of medical research by minority populations (Moreno-John et al. 2004), and characteristics of clinical trial sites that increase the likelihood of recruiting participants with limited health literacy (Livaudais-Toman et al., 2014).

Kaplan CP, Nápoles AM, Narine S, Gregorich S, Livaudais-Toman J, Nguyen T, Leykin Y, Roach M, Small EJ. Knowledge and attitudes regarding clinical trials and willingness to participate among prostate cancer patients. *Contemp Clin Trials*. 2015 Nov;45(Pt B):443-448. doi: 10.1016/j.cct.2015.09.023. Epub 2015 Oct 3. <u>PMID: 26435199</u>.

Through a population-based study of men with early-stage prostate cancer in California, the authors examined associations between race/ethnicity and attitudes, knowledge and willingness to participate in clinical trials. From Nov 2011 to Nov 2012, all incident cases of prostate cancer in African American, Latino, and Asian American men ages 18-75 years were identified, and a random sample of white men diagnosed in 2008, through the California Cancer Registry. Through telephone interviews, they found that compared to non-Latino white men, African American, Asian American, and Latino men were less likely to have above average knowledge of clinical trials. There were no racial/ethnic differences in willingness to participate. The attitude that "researchers are the main beneficiaries" was negatively associated with willingness. The authors concluded that men with early-stage prostate cancer are willing to take part in clinical trials.

Moreno-John G, Gachie A, Fleming CM, Nápoles-Springer A, Mutran E, Manson SM, Pérez-Stable EJ. Ethnic minority older adults participating in clinical research: developing trust. *J Aging Health*. 2004 Nov;16(5 Suppl):93S-123S. doi: 10.1177/0898264304268151. <u>PMID: 15448289</u>.

Mistrust of the scientific community and institutions is a significant barrier to participation in research, and may be a factor in the underrepresentation of African American, Latino, and American Indian older adults in clinical research studies. This article discusses the lack of representation of ethnic minorities in clinical research, and reviews literature regarding medical research mistrust. The authors describe the trust-building activities of the Resource Centers on Minority Aging Research (RCMAR), federally funded centers focused on research and aging in communities of color. The RCMAR centers are building trust with the communities they serve, resulting in the recruitment and retention of ethnic minority older adults in clinical research studies and health promotion projects. Implications are discussed for other researchers toward building trust with ethnic minority elders to increase their participation in research.

Livaudais-Toman J, Burke NJ, Nápoles A, Kaplan CP. Health literate organizations: Are clinical trial sites equipped to recruit minority and limited health literacy patients? *J Health Dispar Res Pract*. 2014;7(4):1-13. PMCID: PMC4540367.

Limited health literacy is a key barrier to participation of minority patients in research. At the organizational level, clinical trial sites need to become better equipped to recruit minority patients by expanding their organizational health literacy including language competency and outreach efforts. The authors explore characteristics of clinical trial sites that are associated with these health literate behaviors. The authors identified 353 breast clinical trials recruiting participants in 2006 from four states (California, Florida, Illinois, and New York) through the National Cancer Institute Physician Data Query system. They contacted one research team member from each site for a survey to assess the site's health literate characteristics. They asked about providing supplementary trial information, offering materials to assist with patient navigation and conducting outreach, offering information in other languages or professional interpretation services. The authors concluded that efforts to recruit diverse participants were limited. Practice type and diversity of patient population were associated with sites' efforts to accommodate these characteristics, suggesting that sites were responsive to the needs of their patients when diversity was prevalent.



Innovative Strategies for Recruiting Diverse Populations

Successful recruitment strategies need to account for numerous factors influencing decisions to participate in research or join a program as noted in our framework above. We feature our innovative efforts using multi-phased approaches to recruiting diverse populations, and also note some other strategies.

Multi-phased strategies: Strategies that entail social influence and change theories and utilize tailored messages and methods are more likely to enroll a representative sample of the target population. Three publications report on use of multi-phased strategies to recruit diverse populations into lifestyle interventions. All began with educational outreach to increase awareness of the importance of lifestyle to health and messages to increase the salience of the topic. After initial contact, eligible individuals are recruited to join a program and research study. By starting with health education, participants are often more interested in a program. In addition, recruiters do not need to spend a lot of time explaining the benefits of the program. Strategies were used to recruit participants into a diabetes risk reduction program (Santoyo-Olsson et al., 2011), into a choir program (Johnson et al., 2017), and into a physical activity promotion program (Mills et al., 1996, 2001).

Mills KM, Stewart AL, King AC, Roitz K, Sepsis PG, Ritter PL, Bortz WM. Factors associated with enrollment of older adults into a physical activity promotion program. *J Aging Health*, 1996;8(1):96-113. <u>PMID</u> 10260566.

In a demonstration study of a physical activity promotion program for seniors (CHAMPS), a proactive two-phased recruitment approach was used to recruit older adults from two lower income congregate housing facilities. An enumeration survey of the entire population (residents) assessed demographics, health, and lifestyle. All residents were invited to a presentation on the importance of physical activity to older adults, and describing the numerous ways to be active (swimming, dancing, walking). The presentation included slides of older adults being active, and included a After the presentation, individuals were invited to enroll. All residents were eligible – there were no exclusion criteria. Overall, 21% of the target population were recruited into the program. Recruitment strategies such as those used in this study appeared to enable enrollment of a reasonably representative sample of a small well-defined population.

Mills KM, Stewart AL, McLellan BY, Verboncoeur CJ, King AC, Brown BW Jr. Evaluation of enrollment bias in a physical activity promotion program for seniors. *J Aging Phys Activity*. 2001, 9(4);398-413. Link to PDF.

In a larger randomized controlled trial of the CHAMPS physical activity promotion program for seniors, the study used an improved version of a 2-phased recruitment approach and explored whether it resulted in recruitment of a representative sample of older adults from a Medicare HMO. Outreach to HMO members included an initial contact letter from a prominent geriatrician and an article in the provider's monthly newsletter. A series of informational meetings described the importance of physical activity to older adults, the numerous ways to be active (swimming, dancing, walking), and described the program and study. Overall, 33% of eligible persons were recruited into the program. A representative proportion of sedentary persons were enrolled, and those who were overweight were overrepresented. However, ethnic minority persons and those with less education were underrepresented. Recruitment strategies such as those used in this study appeared to enable enrollment of a reasonably representative sample of a well-defined population.



Santoyo-Olsson J, Cabrera J, Freyre R, Grossman M, Alvarez N, Mathur D, Guerrero M, Delgadillo AT, Kanaya AM, and Stewart AL. An innovative multiphased strategy to recruit underserved adults into a randomized trial of a community-based diabetes risk reduction program. *Gerontologist*. 2011;51 Suppl 1:S82-93. PMCID: PMC3092977.

The study reports a two-phased community-based approach to recruit lower socioeconomic status, minority, or Spanish-speaking adults at risk of developing diabetes to a randomized trial of a lifestyle intervention program delivered by a public health department. The strategy involved first conducting community-based events to provide diabetes education, administer a short diabetes risk appraisal (DRA), and screening for diabetes risk based on a fasting fingerstick glucose test with immediate results. For those found to be at risk, health educators described the lifestyle program and research and invited them to join. This approach thus substantially engaged individuals prior to inviting them into the study, and provided an incentive to address their individual risk. Over 2 years, approximately 5,110 individuals received diabetes education, 1,917 completed a DRA, and 1,164 were screened of which 641 (55%) had an elevated risk. Of those at risk of developing diabetes, 43% enrolled in the trial. Providing diabetes health education and screening prior to study recruitment may help overcome barriers to research participation in underserved communities, thus helping address difficulties recruiting minority and older populations into research, particularly research pertaining to chronic disease risk factors.

Johnson JK, Gregorich SE, Acree M, Nápoles AM, Flatt JD, Pounds D, Pabst A, Stewart AL. Recruitment and baseline characteristics of the Community of Voices choir study to promote the health and well-being of diverse older adults. *Contemp Clin Trials Commun*. 2017 Dec;8:106-113. PMCID: <u>PMC5791898</u>.

A study to examine the effect of a community choir intervention on the health and well-being of older adults from diverse racial/ethnic and socioeconomic backgrounds. The study identified 12 senior centers and recruited seniors from areas near each center using a variety of methods. Outreach (flyers, word-of-mouth) was done at other center events, and throughout the community (libraries, senior housing) to inform people of the choir program. They were invited to ongoing presentations about the study and program. Bilingual, bicultural research associates described the study, answered questions, and invited participants to be screened. All procedures were conducted at the local senior centers, for convenience to participants. The study contacted 819 individuals, screened 636, and enrolled 390 diverse older adults over a 42-month, phased recruitment period. Outreach and recruitment methods used in the Community of Voices trial facilitated enrollment of a large proportion of minority and lower-SES older adults in the final sample. Similar recruitment approaches could serve as a model for recruiting diverse racial/ethnic and socioeconomic older adults into research.



Other strategies: Two strategies described below are using peers to recruit Latinas with breast cancer into a study to collect biospecimens and how a study added community-based recruitment strategies when random digit dialing methods did not yield sufficient numbers.

Samayoa C, Santoyo-Olsson J, Escalera C, Stewart AL, Ortiz C, Márquez-Magaña L, Urias A, Gonzalez N, Cervantes SA, Torres-Nguyen A, Parada-Ampudia L, Nápoles AM. Participant-Centered Strategies for Overcoming Barriers to Biospecimen Collection among Spanish-Speaking Latina Breast Cancer Survivors. *Cancer Epidemiol Biomarkers Prev.* 2020 Mar;29(3):606-615. PMCID: <u>PMC7062229</u>.

This study developed and tested strategies for collecting biomarkers of chronic stress and premature aging among Spanish-speaking Latina breast cancer survivors. To reduce burden, the study selected non-invasive biomarkers (saliva rather than serum). Engaging community partners in planning, the study developed bilingual multimedia instructional materials. Trained community health workers assisted in recruitment and collection of biospecimens. At baseline, rates of donating salivary DNA for telomere length measurement, saliva for CAR analysis, and hair for cortisol concentration were 98%, 89%, and 52%, respectively. At 6-month follow-up, rates were 83%, 76%, and 55%, respectively. Telephone surveys assessed willingness to participate in future studies, barriers to sample collection, and recommendations for improving the strategies. The majority of participants reported being very willing to provide hair (72%) or saliva (74%) for future studies. Results support the feasibility of collecting biomarkers when patient-centered and culturally tailored recruitment methods are used.

Cabral DN, Nápoles-Springer AM, Miike R, McMillan A, Sison JD, Wrensch MR, Pérez-Stable EJ, Wiencke JK; San Francisco Bay Area Lung Cancer Study. Population- and community-based recruitment of African Americans and Latinos: the San Francisco Bay Area Lung Cancer Study. *Am J Epidemiol*. 2003 Aug 1;158(3):272-9. doi: 10.1093/aje/kwg138. <u>PMID: 12882950</u>.

The authors evaluated population- and community-based recruitment methods in a 1998-2001 case-control study of lung cancer among African Americans and Latinos. Rapid case ascertainment by the tumor registry combined with telephone screening identified 470 (9%) African Americans and 262 (5%) Latinos. When random digit dialing (RDD) and Health Care Financing Administration (HCFA) records failed to yield adequate numbers of controls in appropriate age-gender-ethnicity groups, community-based recruitment methods were used. Demographic characteristics and behavioral and occupational risk factors for controls, by recruitment method, were compared with those for lung cancer cases to evaluate potential bias. The average number of hours spent per control participant recruited was 18.6 for RDD, 11.4 for HCFA, and less than 1 for the community-based methods. The prevalence of smoking-related lung cancer risk factors was significantly higher among African-American community-based controls than for those identified through RDD (p < 0.005). Further assessment of strategies for successful recruitment of minority participants into epidemiologic studies is warranted.



Experimental Studies of the Effectiveness of Different Recruitment Methods

Three publications report on experimental studies comparing different methods of recruitment: 1) a refusal postcard versus no postcard (Verboncoeur et al., 2000), 2) an advanced notice letter about the survey study (Nápoles-Springer et al., 2004), and 3) a research informational pamphlet (Santoyo-Olsson et al., 2012).

Nápoles-Springer AM, Fongwa MN, Stewart AL, Gildengorin G, Pérez-Stable EJ. The effectiveness of an advance notice letter on the recruitment of African Americans and Whites for a mailed patient satisfaction survey. *J Aging Health*. 2004 Nov;16(5 Suppl):124S-36S. doi: 10.1177/0898264304269724. <u>PMID: 15448290</u>.

The authors conducted a nested study of the effectiveness of an advance notice letter (versus no letter) mailed two weeks prior to a mail satisfaction survey in a random sample of 600 African American and White patients ages 50 and older, stratified by ethnicity, sex, and age. The advance letter was independently associated with a completed survey in White patients, but not in African American patients. Being male was independently associated with a completed survey in African American patients and younger age was independently associated with a completed survey in African American patients. The authors concluded that an advance letter was associated with increased response rates in White patients, but not in African American patients.

Verboncoeur CJ, Stewart AL, King AC, Rush S, McLellan BY, Mills K. The use of refusal postcards in recruiting older adults. *Ann Behav Med*. 2000 Fall;22(4):330-3. doi: 10.1007/BF02895670. PMID: <u>11253445</u>.

This article examines whether a refusal postcard makes recruitment more efficient or instead reduces response rates to a telephone survey of older adults. Medicare health maintenance organization (HMO) members received an initial contact letter from a HMO geriatrician. A refusal postcard was included in the first sample (N = 178); however, the remaining six samples did not receive this postcard (N = 1,003). An overall refusal rate of 32% was observed when postcards were included versus a 14% rate of refusal when postcards were excluded (p < .001). Despite the higher refusal rate among the sample receiving the refusal postcard, no significant differences in demographics, health, and health behaviors were observed between the two final sample groups completing the survey. We conclude that refusal postcards greatly increase the refusal rates without offering any prescreening advantage in the recruitment process of older adults and could increase the costs of recruitment for a telephone survey. Furthermore, use of a refusal postcard precludes individuals from making fully informed decisions about participating in research.

Santoyo-Olsson J, Phan L, Stewart AL, Kaplan C, Moreno-John G, Nápoles AM. A randomized trial to assess the effect of a research informational pamphlet on telephone survey completion rates among older Latinos. *Contemp Clin Trials*. 2012 Jul;33(4):624-7. PMCID: <u>PMC3361585</u>.

A nested recruitment study explored the effects of a research informational pamphlet produced by the federal Office for Human Research Protections on telephone survey participation rates of older Latino patients. Latino patients aged \geq 50 were sampled from three community clinics and a multi-specialty medical group. Patients were randomly assigned to receive or not receive a pamphlet that contained information on research participation in the initial mailing for the telephone survey study. Women and those with public insurance (vs. no insurance) were more likely to participate, while those age 65+ (vs. age 50-54) were less likely to participate; there was no significant difference by pamphlet group. The authors concluded that recruitment methods that are more intensive than a pamphlet may be needed to enhance survey participation rates among older Latino patients. Nesting of the randomized trial of the recruitment pamphlet within the funded study required minimal additional resources.



Feasibility of Recruitment: Guidelines

Stewart AL, Nápoles AM, Piawah S, Santoyo-Olsson J, Teresi JA. Guidelines for evaluating the feasibility of recruitment in pilot studies of diverse populations: An overlooked but important component. *Ethn Dis.* 2020 Nov 19;30(Suppl 2):745-754. PMCID: <u>PMC7683033</u>.

Conducting a pilot feasibility study of recruitment in which data are collected systematically on recruitment processes can help investigators refine methods for the larger study. However, there are few guidelines for conducting pilot feasibility studies, and recruitment methods are seldom the focus. Feasibility indicators differ from traditional reports of recruitment results by focusing on the extent to which recruitment goals are met. The authors present an organizing framework for assessing the feasibility of recruitment that includes eight steps, briefly: 1) specify recruitment goals; 2) specify recruitment processes; 3) establish a tracking system for each individual; 4) establish a tracking database for monitoring processes and results; 5) implement recruitment and track each individual's progress; 6) summarize recruitment results; 7) calculate and interpret feasibility measures - were goals met; and 8) if goals were not met, utilize tracking data to modify methods for the larger study. Methods are described for each step, with added details for steps 2-5 (the specific processes). The framework draws from a small literature on recruitment feasibility with a focus on health disparities populations. The guidelines blend well-known methods of recruitment with additional information on calculating feasibility indicators. These guidelines provide a first step in thinking systematically about recruitment feasibility, to advance the field of measuring feasibility. Feasibility indicators also can be used to track the effectiveness of innovative recruitment strategies as part of building the science of recruitment, especially in disparities populations.