

Research Methods and Technology Research Article

Cite this article: Kanaya AM, Chang A, Schembri M, Puri-Taneja A, Srivastava S, Dave SS, Vijayakumar EN, Qamar Z, Naik HD, Siddiqui F, and Kandula NR (2019) Recruitment and retention of US South Asians for an epidemiologic cohort: Experience from the MASALA study. *Journal of Clinical and Translational Science* 3: 97–104. doi: [10.1017/cts.2019.371](https://doi.org/10.1017/cts.2019.371)

Received: 12 December 2018
Revised: 28 March 2019
Accepted: 9 April 2019
First published online: 27 May 2019

Key words:

Ethnic minority; recruitment; retention; longitudinal study; epidemiology

Address for correspondence:*A. Kanaya, MD, 1545 Divisadero Street, Suite 311, San Francisco, CA 94115, USA.
Email: alka.kanaya@ucsf.edu

© The Association for Clinical and Translational Science 2019. This is an Open Access article, distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives licence (<https://creativecommons.org/licenses/by-ncnd/4.0/>), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is unaltered and is properly cited. The written permission of Cambridge University Press must be obtained for commercial re-use or in order to create a derivative work.



Recruitment and retention of US South Asians for an epidemiologic cohort: Experience from the MASALA study

Alka M. Kanaya^{1,*}, Ann Chang¹, Michael Schembri¹, Ankita Puri-Taneja², Shweta Srivastava¹, Swapna S. Dave², Evangeline N. Vijayakumar¹, Zubaida Qamar^{1,3}, Hemalatha D. Naik², Faiza Siddiqui² and Namratha R. Kandula^{2,4}

¹Department of Medicine, University of California, San Francisco, San Francisco, California, USA; ²Department of Medicine, Northwestern University, Chicago, Illinois, USA; ³Family, Interiors, Nutrition and Apparel Department, San Francisco State University, San Francisco, California, USA and ⁴Department of Preventive Medicine, Northwestern University, Chicago, Illinois, USA

Abstract

Introduction: There are few longitudinal studies about South Asians (SAs) and little information about recruitment and retention approaches for this ethnic group. **Methods:** We followed 906 SAs enrolled in the Mediators of Atherosclerosis in South Asians Living in America (MASALA) cohort for 5 years. Surviving participants were invited for a second clinical exam from 2015 to 2018. A new wave of participants was recruited during 2017–2018. We assessed the yields from different methods of recruitment and retention. **Results:** A total of 759 (83%) completed the second clinical exam, and 258 new participants were enrolled. Providing a nearby community hospital location for the study exam, offering cab/shared ride reimbursement, and conducting home visits were the most effective methods for enhancing retention. New participant recruitment targeted women and individuals with lower socioeconomic status, and we found that participant referrals and active community engagement were most effective. Mailing invitational letters to those identified by electronic health records had very low yield. **Conclusion:** Recruitment and retention strategies that address transportation barriers and increase community engagement will help increase the representation of SAs in health research.

Introduction

South Asians (SAs), individuals from India, Pakistan, Nepal, Bangladesh, and Sri Lanka, comprise nearly a quarter of the global population with over 25 million residing in diaspora countries. There are approximately 5 million residents of SA origin in the USA [1]. SAs are the second largest Asian subgroup and are the second fastest growing ethnic group in the USA after Latinos [2]. SAs have a unique phenotype with a high prevalence of early onset cardiovascular disease (CVD)[3,4] where conventional risk factors (age, sex, smoking, obesity, diabetes, cholesterol, and hypertension) do not fully explain this heightened disease risk [3,5]. To fill this gap in knowledge, the National Heart, Lung, and Blood Institute supported the creation of the Mediators of Atherosclerosis in South Asians Living in America (MASALA) prospective cohort study to investigate the prevalence and risk factors associated with subclinical atherosclerosis at baseline and incident CVD events among a community-based sample of SAs in the USA aged 40–84 years without known CVD [6].

We completed the second clinical exam of the MASALA study and enrolled a new wave of participants by March 2018. We describe the methods employed for participant follow-up/retention and the new wave of recruitment, compare characteristics of the new enrollees with the original cohort and the participants who did not follow-up, and discuss the barriers and facilitators for retention and recruitment of SA participants in a longitudinal cohort.

Materials and Methods

Our original study eligibility and recruitment methods have been described previously [6]. The MASALA study was conducted at two academic institutions, the University of California San Francisco (UCSF) and Northwestern University (NU). A total of 906 community-dwelling participants from the San Francisco Bay area and the greater Chicago area were recruited at baseline (2010–2013). A new wave of participants was recruited from March 2017 to March 2018 (Fig. 1). The study was approved by the institutional review boards at UCSF and NU.

Briefly, to be eligible for the MASALA study, participants had to (1) self-identify as SA; (2) be between 40 and 84 years of age; and (3) have the ability to speak and/or read English, Hindi, or Urdu. The remaining eligibility criteria were identical to the Multi-Ethnic Study of

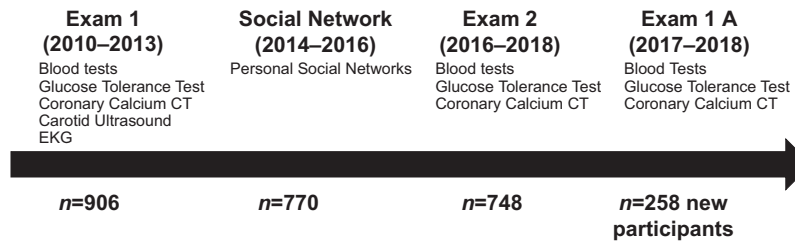


Fig. 1. Flow diagram for the MASALA study exams. EKG = electrocardiogram; CT = computed tomography.
Note: Each study exam is shown with the dates and numbers of participants.

Atherosclerosis (MESA) [7] and excluded those who had heart attack, stroke or transient ischemic attack, heart failure, angina, use of nitroglycerin, a history of CVD procedures or any surgery on the heart or arteries, current atrial fibrillation, or active treatment for cancer. Individuals with life expectancy <5 years, those with impaired cognitive ability, or those who planned to move out of the study region in the next 5 years were also excluded. For our second wave of participant recruitment, we used a higher age criterion of 50–84 years, so that new participants would be similar in age to those already enrolled in the cohort. Written informed consent was obtained from all participants at the start of each exam visit. Consent forms were translated into Hindi and Urdu and trained bilingual research coordinators obtained consent.

Retention Methods

After the baseline exam visit, each participant received an annual study newsletter, a birthday card, and a holiday card (Diwali, Eid, or Christmas, as appropriate based on their religious affiliation). We organized community forums to disseminate baseline MASALA study results to participants/community members and held several health and wellness events for participants. We contacted each participant annually for a brief follow-up by phone [6] and/or by email [8] to ascertain general health status and asked about any new health diagnoses, procedures, hospitalizations, or intervening CVD events.

Ancillary and Second Clinical Exam

In September 2014, we began a social networks ancillary study inviting all surviving MASALA study participants for a 2-hour interview with physical exam measurements (Fig. 1) [9]. The data collection for the social networks study did not include any blood draws or imaging procedures, and most visits were conducted in convenient community locations or in the participant's home. Participant remuneration for this brief visit was \$25.

In September 2015, participants were contacted by email and also mailed invitational letters to return for a second clinical exam which included fasting blood tests, an oral glucose tolerance test (OGTT, for those without known diabetes), anthropometry, seated blood pressure, and a repeat non-contrast cardiac computed tomography (CT) scan for coronary artery calcium (total exam time of 2–3 hours). Participant remuneration for Exam 2 was \$25 to help to pay for transportation and parking costs. We first contacted participants who had not completed the social networks ancillary study and combined both Exam 2 and social networks data collection together in a 3–4 hour study visit. Participants who completed both study visits together received \$50 remuneration.

Assessing and Addressing Participant Burden for Exam 2

In mid-2016, we informally asked participants about the barriers and facilitators that would make it easier for them to attend and complete Exam 2. In late 2016, we started employing new approaches to engage and retain participants to help overcome the main barriers of distance, time, and transportation and also to increase their understanding and engagement in the study. We offered the new retention strategies as several options to participants who had not responded to our initial invitation (by mail and phone). We report the additional cost for each of these retention approaches exclusive of the time and effort by our research study staff.

To lessen participant time and travel burden, we opened two new suburban clinical sites (both through Northwestern Medicine, in Winfield and Glenview, Illinois) approximately 35 miles east and 15 miles north of Chicago, respectively. These locations were much closer to participants' homes. Participants who reported being too frail to take public transportation or drive to the clinical exam were offered a cab or shared ride reimbursement from their homes, or a MASALA staff member to travel with him/her to the clinic site, or an abbreviated home visit which would not include an OGTT or CT scan. We also provided Saturday appointments at both the UCSF and NU sites, offered raffle prizes to exam completers, and had the principal investigator (PI) at each site perform telephone outreach. Participants who had moved out of the geographic area of the clinical site were offered an airline or train ticket, a one-night hotel stay, meals, and taxi transfers to attend the clinical exam. We also conducted monthly community workshops in different geographic locations at each clinical site to disseminate MASALA study findings and provided education about wellness topics such as mindfulness, stress reduction, yoga, healthy SA cooking, and resistance exercise training. At these community events, the PI and study staff would briefly describe study progress and emphasize the importance of longitudinal follow-up and completing clinical Exam 2.

There were two additional retention strategies employed by the NU site in mid-2017. Participants were invited to bring in their spouse for a limited exam with free fasting blood test and other physical exam measurements. The NU site also increased remuneration to \$150 during the last 2 months of the study period to help overcome time and transportation barriers.

Recruitment of 2nd Wave of Participants

Our goal was to recruit approximately 250 new participants into the MASALA study to increase the overall size of the cohort. To create internal diversity in our study population, we purposefully targeted recruitment to include more SA women and include groups that were relatively under-represented in our original

cohort (those born in SA countries other than India) and those with lower socioeconomic status.

Our two field sites used three primary methods of recruitment, allowing each site to use the strategies that would be most effective based on their experience with working with the SA community and organizations locally. First, we engaged community organizations that serve SAs and study staff presented informational sessions about the goals and findings to date of the MASALA study. At UCSF, we engaged community leaders in the Pakistani, Bangladeshi, and general Muslim communities and gave talks about SA heart disease and the goals of the MASALA study in different community settings (Pakistani American Association, South Bay Islamic Association, Muslim senior support network, and a Bangladeshi community group). At these community informational seminars, we collected contact information from attendees who were interested in learning more about the study and being screened for eligibility. As a distinct method of community outreach, the NU site also hired a community recruiter who was a staff at an SA community organization; this individual recruited individuals into the study through face-to-face recruitment at local religious and community organizations. The community recruiter used fliers and explained the study to people. The recruiter provided the contact information of interested individuals to Northwestern field center staff who followed up with a telephone call in 1 week.

Second, we used a chain referral approach and asked current study participants to recommend up to three unrelated SA contacts (with no monetary incentive for the referral). This chain referral approach utilized a snowball sampling method and is commonly used in studies of harder to reach populations [10]. Once the contact information was obtained for these referred individuals, study staff screened the person for eligibility by phone and determined whether the individual already had a household or family member in the study as an additional exclusion criterion. Newly recruited participants were also asked to refer up to three individuals into the study after completing their exam visit to create separate waves of recruitment that extended beyond the current participants.

Lastly, the NU site used the electronic health record (EHR) at Northwestern Medicine to generate lists of patients from the healthcare system who may be potentially eligible for the MASALA study. Individuals of SA origin were identified using an SA surname list [11]. After receiving permission to contact the patient from their primary care provider (PCP), these letters were personalized and were signed by the MASALA study PI. We mailed invitational letters and brochures to random batches of these patients and called them within 2 weeks to determine their eligibility and interest in participating in the study. Because these individuals were already patients of the healthcare system, we expected fewer barriers to participation in the clinical exams and better access to health records for ascertainment of CVD events.

Statistical Analyses

We compared participant characteristics between those who completed Exam 2 and the newly recruited individuals, and also compared Exam 2 participants with non-responders using chi-squared tests and *t*-tests for these comparisons. We used SAS, version 9.3 (SAS Institute) for our analyses.

Results

After a median 4.8 years of follow-up, a total of 749 (83%) of the surviving MASALA cohort ($n = 900$) participated in Exam 2 with

higher retention at the UCSF site compared to NU (88% vs 76%). Another 258 participants were recruited in the second enrollment wave (called Exam 1A), with 55% recruited from the greater Chicago area and 45% from the San Francisco Bay area. Table 1 shows the demographic characteristics of the MASALA study cohort at each exam and the new wave of enrollees. The new enrollees in Exam 1A were older than Exam 2 participants, had lived in the USA for fewer years, were more likely to be from Pakistan and Sri Lanka, and had lower educational attainment compared to existing participants. Fig. 2 compares the participants who completed Exam 2 with the surviving cohort participants who did not return for Exam 2. Compared to participants who completed Exam 2, non-responders were more likely to be women, Pakistanis, Muslim, and have lower educational attainment.

To develop relevant retention approaches, we contacted participants by phone and with emails to assess barriers for follow-up and found that the clinic location, travel logistics, and overall time for the study visit were the biggest barriers to continued participation. The clinical exam protocol included a fasting blood draw, a 2-hour OGTT, a cardiac CT scan, along with physical exam measurements and questionnaires which took on average 3–4 hours to complete. While some participants felt that these tests were incentives because they are not routinely provided as part of medical care, some individuals feared repeating the CT scan in the second exam due to possible harm from radiation, and several reported discomfort with the oral glucose solution for the OGTT. Participants were able to opt out of any tests or procedures that they did not wish to perform (91 did not do the OGTT and 47 participants did not complete the CT scan during Exam 2, which includes the 29 people who did home-based visits).

Several of our newer retention approaches were helpful for Exam 2 completion (Table 2). The NU field site opened two new community hospital locations (in Winfield and Glenview, Illinois) that approximately half of all of the participants ($n = 150$) preferred for their study exam than the downtown Northwestern University Medical Center. The overall cost associated with training and certifying the nursing and laboratory staff on the study protocol was approximately \$2800 at each of the two hospital locations. Another approach that was helpful in retaining participants ($n = 51$) was to provide reimbursement for a taxi or shared ride cost to travel to the clinical exam. The average cost of this transportation expense was \$132 at UCSF and \$85 at NU. Another useful retention method was conducting abbreviated exams in the participant's home. With transportation cost for the staff member and phlebotomist to draw the blood samples and transport them to the lab and clinical site, the average additional cost for the home visit was \$140 per participant. As a novel retention strategy, the NU site allowed a participant to bring in a family member (most commonly a spouse) who would receive a limited free clinical exam with fasting laboratory tests (for an additional cost of \$41 per participant), which resulted in approximately 29 retained participants. Travel reimbursement for people who had moved away from the geographic area helped to retain eight respondents (average cost of \$600), and higher remuneration for exam completion was used by six respondents.

Recruitment yield for our new wave of enrollment is shown in Fig. 3. We identified a total of 1067 individuals (317 at UCSF and 750 at NU) over the course of 1 year (March 2017–Feb 2018) comprising our total recruitment pool. Approximately 55% of the recruitment pool at NU was derived from the EHRs at NU medical center, but the participants who enrolled using this approach was lowest; only 5% of those who were mailed invitational letters enrolled in the study. The EHR recruitment cost was approximately \$5000 or

Table 1. Characteristics of Mediators of Atherosclerosis in South Asians Living in America (MASALA) participants at each clinical exam

	Exam 1 N = 906	Exam 2 N = 749	New wave (Exam 1A) N = 258	P-value comparing Exam 2 vs Exam 1A
Sex, female	420 (46)	335 (45)	136 (53)	0.03
Study site				<0.001
Northwestern	410 (45)	314 (42)	141 (55)	
University of California, San Francisco (UCSF)	496 (55)	435 (58)	117 (45)	
Age, years	55 ± 9	60 ± 9	62 ± 80	<0.001
40–49 years	293 (32)	116 (16)	0	0.75
50–59 years	302 (33)	286 (38)	115 (45)	
60–69 years	235 (26)	215 (29)	95 (37)	
70–79 years	73 (8)	120 (16)	46 (18)	
≥80 years	3 (0.3)	12 (2)	2 (1)	
Years in the USA	27 ± 11	32 ± 11	29 ± 14	0.006
0–10	52 (6)	16 (2)	32 (13)	<0.001
11–20	225 (25)	117 (16)	47 (18)	
21–30	257 (29)	216 (30)	51 (20)	
31–40	242 (27)	205 (28)	69 (27)	
≥40 years	111 (12)	176 (24)	56 (22)	
Country of birth:				<0.001
India	757 (85)	631 (84)	208 (81)	
Pakistan	41 (4)	24 (3)	26 (10)	
Sri Lanka	9 (1)	9 (1)	10 (4)	
Bangladesh	5 (1)	3 (0.4)	1 (0.4)	
Nepal	4 (0.4)	1 (0.1)	0	
USA	19 (2)	19 (2)	2 (1)	
Other	71 (8)	62 (8)	11 (4)	
Educational attainment:				<0.001
High school or equivalent	61 (7)	42 (6)	29 (11)	
< Bachelor's degree	49 (5)	36 (5)	19 (7)	
= Bachelor's degree	261 (29)	212 (28)	94 (36)	
> Bachelor's degree	535 (59)	459 (61)	116 (45)	
Family income:				<0.001
<\$50,000	155 (18)	104 (14)	66 (27)	
50,000–\$74,999	80 (9)	66 (9)	25 (10)	
\$75,000–\$99,999	89 (10)	74 (10)	23 (9)	
≥\$100,000	556 (63)	483 (66)	132 (54)	
Religious affiliation:				<0.001
Hindu	612 (68)	519 (69)	171 (66)	
Muslim	64 (7)	38 (5)	44 (17)	
Sikh	69 (8)	59 (8)	7 (3)	
Jain	56 (6)	49 (7)	18 (7)	
Other	47 (5)	36 (8)	22 (9)	
None	58 (6)	48 (6)	6 (2)	

Values represent *n* (%) or mean ± SD.

Age and years lived in the USA are estimated with a censoring date of March 1, 2018.

\$227 per enrolled participant. The community outreach had a higher yield and was similar at both sites with about 28–30% enrollment of those who provided contact information. NU received more contacts through the community recruiter than by direct community outreach events held by the study staff. However, the proportion of eligible and enrolled participants was higher with the field center staff's community outreach than by using a community recruiter (57% vs 26%). The additional cost for the community recruiter method was \$4440 or approximately \$78 per enrolled participant. The participant chain referral method had the highest yield overall with no additional cost, with 42% at UCSF and 51% at NU enrollment from this approach. However, only 9% of participants from NU and 18% of participants from UCSF referred their friends, and the average number of referrals was 1.6 and 1.9, respectively. A total of 89 (8.3%) individuals who were screened for the study were found to be ineligible, and the primary reason for ineligibility overall was existing CVD. Of

those who were eligible for participation, 50 (4.7%) were not interested in enrollment. A total of 258 SAs, or 82% of those who were found to be eligible, enrolled in Exam 1A, which was 24% of the overall recruitment pool.

Discussion

SAs are underrepresented in health research, and the challenge of recruiting and retaining SAs into clinical research studies remains a key issue. In this first longitudinal cohort study of SAs in the USA, the overall retention after approximately 5 years of follow-up was 83%. We found that older participants, women, Muslims, and individuals from lower socioeconomic strata were less likely to follow-up during the second clinical exam. Providing study exams at community hospital sites closer to where participants lived, offering cab or shared ride reimbursement to and from the clinical site, allowing

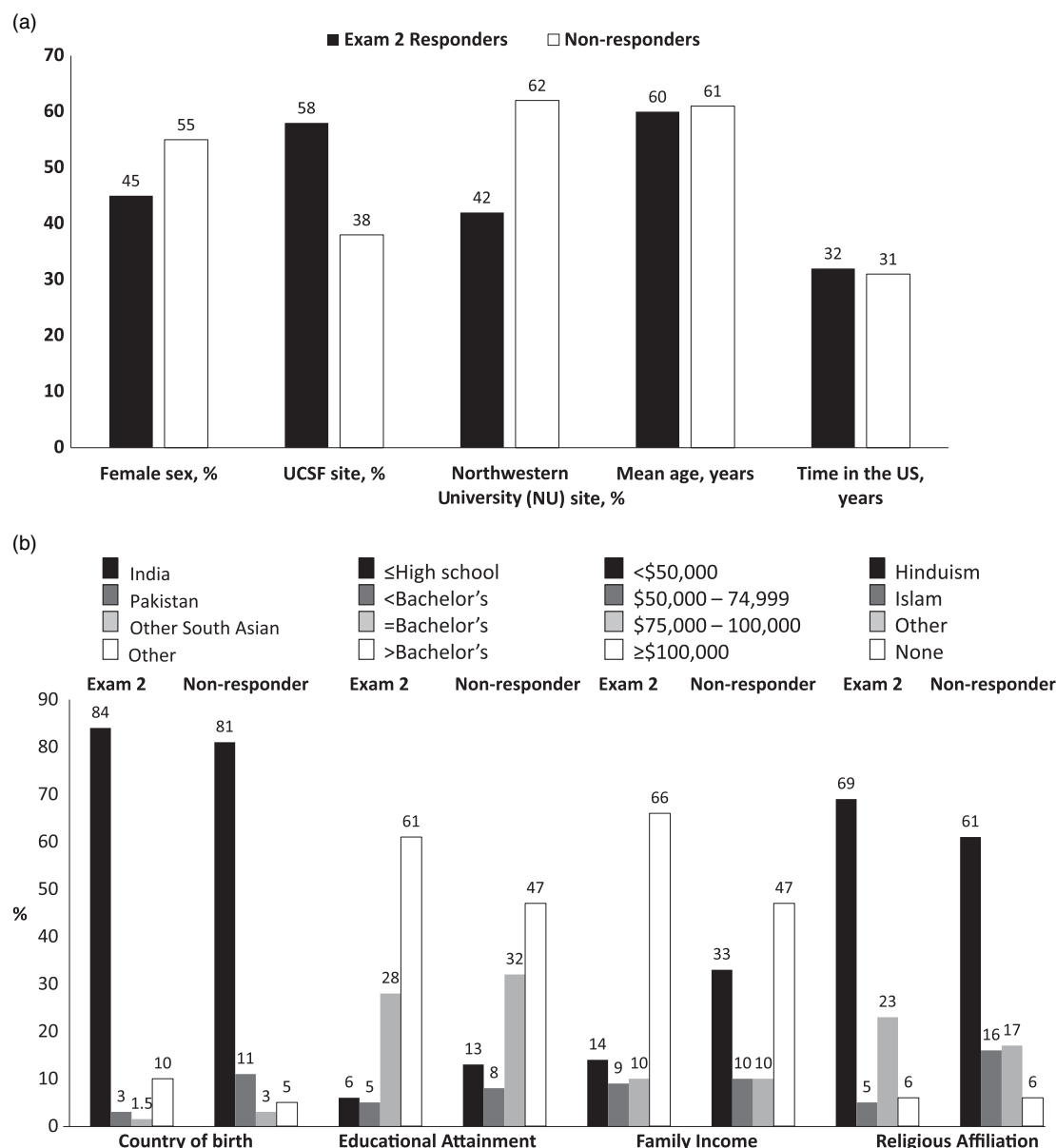


Fig. 2. Characteristics of Mediators of Atherosclerosis in South Asians Living in America (MASALA) participants who completed Exam 2 compared to non-responders. Notes: Panel A shows demographic characteristics of responders vs non-responders. Panel B shows the nativity, socioeconomic status, and religious affiliation categories of responders vs non-responders.

limited laboratory testing for a family member, and conducting home visits for elderly or frail participants were the most effective methods that bolstered study retention. For our new wave of recruitment, we preferentially targeted the sociodemographic groups with poor retention using new recruitment and engagement methods to broaden the overall generalizability of our cohort. We found that participant referrals and active community engagement by study staff and a community recruiter were the best methods for recruiting eligible participants, whereas using EHRs data to mail invitational letters had a very low yield.

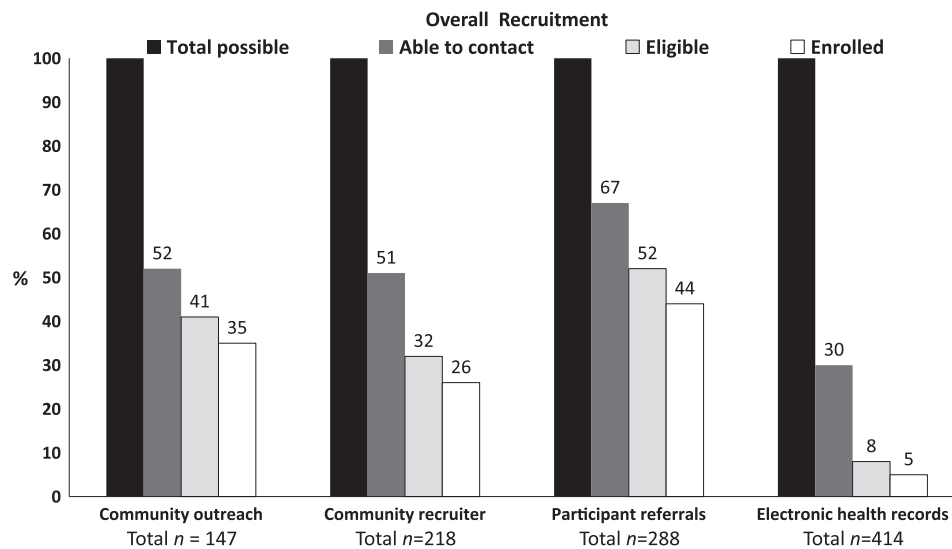
Very few studies have long-term follow-up of SA (>3 years) and only a handful of studies have reported or analyzed their retention methods even for shorter-term studies [12–14]. Some strategies to aid retention that have been suggested for intervention studies in SA included providing meaningful incentives (including free transportation and childcare), hiring culturally concordant community

health workers, and having flexibility in scheduling study visits [12–14]. Retention strategies that have been successful in other race/ethnic groups including African Americans and other lower-income populations in the USA include incentives, personal approach, utilizing a dedicated phone line, project identity and logos, participant convenience, and repeated contact with participants [15,16]. As a result of informal participant feedback about the barriers for continued participation, we implemented several new strategies including opening new community hospital locations for the clinical exam, providing local and long-distance travel reimbursements, and home visits. While several of these strategies required more resources, they greatly reduced participant burden and improved study retention. An innovative strategy that has not been described previously was the use of a limited exam with laboratory tests for the participant’s spouse at the NU (Chicago) site. This strategy may be important for retention and engagement of

Table 2. Participants seen using newer retention methods

	Overall <i>n</i> = 749	University of California, San Francisco (UCSF)* <i>n</i> = 438	Northwestern University (NU)* <i>n</i> = 311
Community hospital clinic sites, %	20.0	–	48.2
Taxi or shared ride reimbursement, %	6.8	6.6	7.1
Spousal limited visits, %	3.9	–	9.3
Home visits, %	3.6	4.1	3.2
Travel reimbursement (long-distance), %	1.1	0.9	1.3
Increased remuneration to \$150 from \$25, %	0.8	–	1.9
Accompanied by staff to clinic appointment, %	0.7	1.1	–
Total retained with these methods	276 (36.8%)	56 (12.8%)	221 (71.1%)

*Three participants moved from the Chicago area to the San Francisco Bay area between Exam 1 and Exam 2 and were seen at the UCSF field site.

**Fig. 3.** Recruitment approaches for the new wave of participants in Mediators of Atherosclerosis in South Asians Living in America (MASALA), 2017–2018.

Notes: We show the overall numbers of people who we attempted to contact below each category (black bar = 100% of total possible), and the gray and white bars represent the percent who were contacted, those who were eligible, and those who enrolled by each type of recruitment method.

SA populations where family plays an important role in health-related decisions. We found that women, in particular, brought their spouses to these limited visits. This strategy was used only at the NU site, where retention of women was more challenging than at the UCSF site, highlighting the need for strategies that may vary across SA groups and those living in different regions.

In our second wave of recruitment for the MASALA study, we employed three different strategies that were not used in our original cohort recruitment during 2010–2013 using recommendations from the recent reviews [17, 18]. Based on our participant demographic characteristics and early study retention results, we created three new approaches to reach women, older individuals, non-Indian SA, and individuals with lower educational attainment. We found that the community outreach and community recruiter approach were helpful in recruiting these more vulnerable populations. We learned that it was important to spend time at community events and provide concrete examples of how research could benefit the SA community and why longitudinal follow-up is important. Effective strategies are needed to increase the SA community's trust and understanding of scientific research. Future studies should consider how to engage SA community members

throughout the research study, conduct research that includes community priorities, and include community members as part of the study team [19]. Recruitment and retention of diverse populations are necessary to increase the impact and generalizability of scientific research, and community-engagement strategies are increasingly being incorporated into study design [16, 20].

We also used chain referral with a snowball sampling method and asked our participants to refer up to three of their SA friends or acquaintances who may be eligible and interested in study participation. We hypothesized that this method would be effective as it has been used in several studies of ethnic minority populations in the USA. However, we found that relatively few referrals were made by the NU participants in MASALA compared to the UCSF participants. But this was the most effective method with highest yield for enrolling new participants from both sites. Although chain referral methods are commonly used in studies of harder to reach groups, including immigrants, this method is prone to sampling biases because individuals have an unequal probability of selection. Another chain referral method is respondent-driven sampling [21]; however, this approach would have required more resources for tracking and incentive payouts for referrals [22].

We used the EHR data of Northwestern Medicine to identify and invite SAs who were patients at and familiar with the health-care setting for study screening. This strategy was expensive and had low efficacy in enrolling new participants. One weakness of our EHR approach was that we did not engage health providers heavily in our recruitment; PCPs were informed that their patients would be receiving a recruitment letter and that they could opt out. Other studies suggest that greater PCP involvement may lead to better yield when using EHR recruitment [17].

Several prior studies have examined strategies for improving recruitment in SA communities [12, 17, 18, 23, 24]. A recent scoping review by Quay and colleagues which included 15 articles that discussed barriers and facilitators for recruitment of SA found that the main facilitators were perceptions for improved treatment and health for themselves, altruistic beliefs about contributing to general health knowledge, and a sense of obligation to their healthcare providers [17]. Major barriers to recruitment included disinterest or lack of feeling of belonging, conflicts, education- or training-related deficits, logistical or opportunity costs, fears and inhibitions, and research-related barriers [17]. Recommended recruitment strategies included language and culturally driven methods, communication and engagement strategies, logistical changes and accommodations, policy and study design measures, and incentives [17]. Another recent paper by Mukherjee *et al.* described four different research studies of SAs in the USA and discussed facilitators and barriers of recruitment for each [18]. Some promising recruitment strategies proposed include active recruitment with community talks and follow-up from study staff, providing appropriate incentives, engaging cultural research brokers, and having trusted sources of information [18].

Several systematic and qualitative reviews have examined the barriers and facilitators for race/ethnic minority group participation in clinical research studies [16, 20, 25, 26]. A recent comprehensive review of studies that included African Americans, Latinos, Asian Americans, and Pacific Islanders found that of the 44 studies reporting perceived barriers and facilitators to participating in health research between 2000 and 2011, there were many shared and distinct barriers and facilitators among the different ethnic minority groups [26]. Shared barriers to research participation included mistrust, competing demands, unintended outcomes, lack of access to information, stigma, health insurance coverage, and legal status in the USA, while shared facilitators included cultural congruence, benefits to participation, altruism, convenience of participation, and low risk in participation [26]. Distinct barriers that were unique to African Americans included a legacy of mistrust; in Asian Americans included lack of social support and acculturation; and in Pacific Islanders included misrepresentation of community. Distinct facilitators among African American studies were the design and logistics including safety assurances, trust in the researcher, having treatment options, and inclusion of diverse race/ethnic groups including Whites in the study; for Asian Americans, a distinct facilitator was endorsement from family members; and for Pacific Islanders, it was community mediation of how research findings are used and reported [26]. Our work with SAs found similar shared beliefs in the barriers and facilitators, but distinct facilitators were to have community and social network buy-in to the research. The community outreach, community recruiter, and participant referrals were the most helpful strategies in SA recruitment.

The MASALA study's strengths are that it is the only longitudinal study of a community-based cohort of SAs in the USA, and the study's design enables the comparison of prevalence

and risk associations with four other US race/ethnic groups in the MESA study [27]. However, this cohort only includes SAs from two geographic locations in the USA, and those between ages of 40 and 84 years who have no existing CVD, limiting our ability to generalize the results to all US SAs. While the demographic and socioeconomic distribution represented in this age group is grossly representative of the US SA population from Census 2010 [2], a majority of the MASALA cohort has high socioeconomic attainment and is of Indian origin.

The MASALA study had high overall study follow-up with the use of newer retention strategies that reduced participant burden associated with time and travel distance and increased spousal engagement in the study. We used different recruitment strategies to enroll a new wave of participants from sociodemographic groups that historically have had lower retention. The two recruitment methods that were most successful were participant referrals and community-based outreach by study staff. These retention and recruitment strategies may be helpful to future studies of SAs in diaspora countries. It is imperative for studies of SAs to report and analyze effective methods for engaging participants in research studies, so that there is adequate representation and generalizability of results for this diverse ethnic group.

Acknowledgments. The authors thank the study participants and other members of the study team. The MASALA study was supported by the NIH grant numbers 1R01HL093009, 2R01HL093009, and R01HL120725. Data collection at UCSF was also supported by UCSF-CTSI grant numbers UL1RR024131 and UL1TR001872, and P30DK098722. The new wave of participants was supported in part by an anonymous donor to Dr. Alka Kanaya. The sponsors did not play a significant role in the analysis, interpretation, and presentation of these results.

Disclosures. The authors have no conflict of interest to declare.

References

1. **American Community Survey.** *B02015 ACS Asian Alone by Selected Groups, 2017 ACS 1-Year Estimates.* 2017; 2018.
2. **U.S. Census Bureau.** *2010 Census – Demographic Profile Data;* 2010.
3. **Joshi P, et al.** Risk factors for early myocardial infarction in South Asians compared with individuals in other countries. *JAMA* 2007; **297**: 286–294.
4. **Zaman MJ, Bhopal RS.** New answers to three questions on the epidemic of coronary mortality in South Asians: incidence or case fatality? Biology or environment? Will the next generation be affected? *Heart* 2013; **99**: 154–158.
5. **McKeigue PM, Miller GJ, Marmot MG.** Coronary heart disease in South Asians overseas: a review. *Journal of Clinical Epidemiology* 1989; **42**: 597–609.
6. **Kanaya AM, et al.** Mediators of Atherosclerosis in South Asians Living in America (MASALA) study: objectives, methods, and cohort description. *Clinical Cardiology* 2013; **36**: 713–720.
7. **Bild DE, et al.** Multi-ethnic study of atherosclerosis: objectives and design. *American Journal of Epidemiology* 2002; **156**: 871–881.
8. **Kandula NR, et al.** Mediators of Atherosclerosis in South Asians Living in America: use of web-based methods for follow-up and collection of patient-reported outcome measures. *JMIR Research Protocols* 2016; **5**: e95.
9. **Kandula NR, et al.** Personal social networks and organizational affiliation of South Asians in the United States. *BMC Public Health* 2018; **18**: 218.
10. **Bagheri A, Saadati M.** Exploring the effectiveness of chain referral methods in sampling hidden populations. *Indian Journal of Science and Technology* 2015; **8**(30): 1–8.
11. **Lauderdale DS, Kestenbaum B.** Asian American ethnic identification by surname. *Population Research and Policy Review* 2000; **19**: 283–300.

12. **Waheed W, et al.** Recruitment strategies for British South Asians in 5 depression trials: a mixed method study. *Journal of Affective Disorders* 2015; **185**: 195–203.
13. **Islam NS, et al.** Evaluation of a community health worker pilot intervention to improve diabetes management in Bangladeshi immigrants with type 2 diabetes in New York City. *The Diabetes Educator* 2013; **39**: 478–493.
14. **Islam NS, et al.** Diabetes prevention in the New York City Sikh Asian Indian community: a pilot study. *International Journal of Environmental Research and Public Health* 2014; **11**: 5462–5486.
15. **Nicholson LM, et al.** Recruitment and retention strategies in longitudinal clinical studies with low-income populations. *Contemporary Clinical Trials* 2011; **32**: 353–362.
16. **Nicholson LM, Schwirian PM, Groner JA.** Recruitment and retention strategies in clinical studies with low-income and minority populations: progress from 2004–2014. *Contemporary Clinical Trials* 2015; **45**: 34–40.
17. **Quay TA, et al.** Barriers and facilitators to recruitment of South Asians to health research: a scoping review. *BMJ Open* 2017; **7**: e014889.
18. **Mukherjea A, et al.** Overcoming challenges in recruitment of South Asians for health disparities research in the USA. *Journal of Racial and Ethnic Health Disparities* 2018; **5**: 195–208.
19. **Selker HP, Wilkins CH.** From community engagement, to community-engaged research, to broadly engaged team science. *Journal of Clinical and Translational Science* 2017; **1**: 5–6.
20. **Butler J, et al.** Characterizing researchers by strategies used for retaining minority participants: results of a national survey. *Contemporary Clinical Trials* 2013; **36**: 61–67.
21. **Heckathorn DD.** Snowball versus respondent-driven sampling. *Sociological Methodology* 2011; **41**: 355–366.
22. **Platt L, Luthra R, Frere-Smith T.** Adapting chain referral methods to sample new migrants: possibilities and limitations. *Demographic Research* 2015; **33**: 665–700.
23. **Douglas A, et al.** Recruiting South Asians to a lifestyle intervention trial: experiences and lessons from PODOSA (Prevention of Diabetes & Obesity in South Asians). *Trials* 2011; **12**: 220.
24. **Mahmood B, Afshar R, Tang TS.** Recruitment and retention of South Asian ethnic minority populations in behavioral interventions to improve type 2 diabetes outcomes. *Current Diabetes Reports* 2017; **17**: 25.
25. **McDougall GJ, Jr., Simpson G, Friend ML.** Strategies for research recruitment and retention of older adults of racial and ethnic minorities. *Journal of Gerontological Nursing* 2015; **41**: 14–23; quiz 24–5.
26. **George S, Duran N, Norris K.** A systematic review of barriers and facilitators to minority research participation among African Americans, Latinos, Asian Americans, and Pacific Islanders. *American Journal of Public Health* 2014; **104**: e16–e31.
27. **Volgman AS, et al.** Atherosclerotic cardiovascular disease in South Asians in the United States: epidemiology, risk factors, and treatments. A scientific statement from the American Heart Association. *Circulation* 2018; **138**: e1–e34.