J. Racial and Ethnic Health Disparities (2018) 5:195–208
DOI 10.1007/s40615-017-0357-x

Overcoming Challenges in Recruitment of South Asians for Health Disparities Research in the USA

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Received: 20 December 2016 / Revised: 25 February 2017 / Accepted: 1 March 2017 / Published online: 31 March 2017

Abstract South Asians—individuals with origins in the countries of Bangladesh, Bhutan, India, Maldives, Nepal, Pakistan, Sri Lanka, and other regions of the subcontinent—are an understudied and at-risk racial/ethnic minority population for disproportionate burden of preventable diseases in the USA. Notwithstanding lack of research disaggregating Asian American subgroups, a key factor in this paucity of data is the lack of participation and engagement of community members in studies which examine distribution and determinants of adverse health outcomes. The purpose of this case study series is to elucidate distinct barriers in recruitment of South Asians in health disparities research within four diverse study designs. These illustrations are followed by a discussion of effective strategies and promising practices to increase and enhance the participation of community members in health-related studies in order to ultimately understand and address disparities among this rapidly growing cultural group in the US systematic collection of data which not only is representative of this understudied population but also elucidates contextual influences on community health and well-being and is pivotal to the reduction and elimination of preventable disparities among South Asians in the USA.

Keywords Recruitment · Diversity · Health disparities · Community engagement · South Asians

Introduction

Addressing health disparities is a key objective of contemporary public health [1]. A critical focus of health disparities research is to accurately and comprehensively understand the role of race and ethnicity, and the independent and interactive role they may play with respect to socioeconomic factors, gender, and other key demographic characteristics [2–4]. Much of the health disparities research has focused on "major" or aggregate racial/ethnic categories (e.g., African American, Caucasian, Hispanic/Latino, American Indian/Alaskan Native), including a combined "Asian/Pacific Islander" ("API") grouping. Asian Americans represent numerous countries, languages, faiths, and other demographic characteristics [5]. Despite calls for disaggregation to reveal considerable differences due to the tremendous social and cultural diversity within this constructed category [6, 7], there remains a notable gap in the collection, analysis, and reporting of health data elucidating disparities and their social determinants among Asian American subgroups [8].

One key issue in health research is the lack of standardized practices for disaggregation of data by meaningful population segments. Moreover, another barrier exacerbating the inability to elucidate granular data about such disparities is the lack of participation by individuals from these populations, such as those from certain Asian American subgroups, in health

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studies. A systematic review demonstrated that common issues precluding participation include mistrust, lack of access to information, stigma, legal status, and competing demands for time across all ethnic groups [9]. For Asian Americans specifically, these barriers were characterized by concerns regarding providing informed consent, lack of time and/or financial resources, intimidation due to English-only materials, family or community judgment ascribed to participation in research, and concerns about impacts on immigration-related processes. On the other hand, facilitators to Asian American participation included cultural congruence (i.e., researchers representative of potential participants, familiarity between participants and research staff, availability of linguistically appropriate study materials and personnel), low perception of risks, benefits outweighing risks and sacrifices, family- or community-driven altruism, and convenience of study times/locations [9].

However, facilitators and barriers to participation by members of diverse Asian American subgroups in health research remain sparse. One such population includes South Asians in the USA, a rapidly growing Asian American subgroup who largely reside in ethnic enclaves with considerable social and cultural distinctions [10, 11]. South Asians—individuals with origins in Bangladesh, Bhutan, India, Maldives, Nepal, Pakistan, and Sri Lanka—exhibit disproportionate burdens of preventable outcomes and demonstrate unique risk factor profiles with respect to a number of social and behavioral factors [12–27]. In investigations which aim to address these disparities, a consistent barrier to more robust and ongoing health research is a lack of understanding on what are the drivers of meaningful participation in health research for South Asians, especially in the USA and other regions of the Diaspora (such as the UK and Canada). Most research regarding engagement of community members has focused on clinical trials, particularly in the UK [27–30]. In the USA, a community-based longitudinal study of South Asians netted an impressive enrollment rate of 60.8% among eligible participants; however, almost three fourths of individuals originally contacted (via mail or telephone) did not reciprocate communication or declined to speak further with researchers regarding the study [31]. The California Health Interview Survey (CHIS), a statewide population-based survey (not offered in South Asian languages), had a response rate of 39.5% from South Asians in 2001 [32], although more recent estimates are not readily available. Studies with smaller regional samples often do not provide response rates and/or report low levels of participation.

The authors of this manuscript have worked extensively in the field of health disparities research, particularly as it pertains to revealing disproportionate burdens of preventable disease among Asian American subgroups. Individually and collaboratively, each author has led studies that have investigated determinants and/or outcomes of concern among South Asians in the USA. Through these collaborations and an ongoing review of relevant literature, it is clear that recruitment of and sustained participation by individuals of South Asian descent poses a considerable and unique challenge in public health and clinical research. Lack of engagement of community members precludes a robust and multidisciplinary understanding of the comparative health profile of South Asians in the USA and ultimately impedes the development and evaluation of targeted strategies to reduce disparities among this understudied and at-risk population. Based on shared experiences of the authors as investigators of the featured studies who have been directly involved in recruitment of South Asians for specific studies each has overseen, coupled with an intent to highlight study designs requiring diverse types of participant involvement, four studies were selected for inclusion in this analysis. The authors were also key collaborators on all or most of these studies. The overarching purpose of this case study series is to elucidate some of the key challenges in recruitment of South Asians into health-related research studies.

Description of Studies in Case Study Series

The four studies highlighted in this case study series analysis were selected largely because of the recent time frame in which they were conducted and an emphasis on generating information necessary for addressing health disparities among South Asians in the USA. The featured research exclusively involved human subjects of South Asian descent (i.e., no comparison studies with participants from other ethnic groups included), and most of whom reside in Northern California. All studies were peer-reviewed by the funding organization, which included federal and state agencies as well as an academic institution; each study received Institutional Review Board approval from its parent institutions (Stanford University, University of California [Berkeley and San Francisco], and Cancer Prevention Institute of California) for data collection from human subjects. Study goals and designs were diverse, included both quantitative and qualitative methods, and utilized varied modalities of data collection, including those used to recruit samples from targeted subgroups. The authors provide a brief structured summary of each study, including purpose and background, relevant methods, and facilitators and barriers related to successful recruitment of participants. Methodological details focus on descriptions of human subject involvement, and recruitment strategies employed to secure participation. Each study description is followed by a detailed reflection on the specific challenges faced by investigators in recruitment of South Asians for participation in their studies. The following text and corresponding table summaries emphasize issues related to the recruitment of South Asians to generate primary data;

other details not directly relevant to securing study participants are not provided.

Case #1: Development of a South Asian Tobacco Use Module

Purpose and Background

The goal of this study, funded by a National Cancer Institute Research Supplement to Increase Diversity in Health-Related Research, was to use community-engaged methods to generate contextual data needed to develop, test, and refine survey items for tobacco surveillance [33]. Tobacco products popular in the South Asian community are mostly limited to smokeless forms indigenous to the subcontinent, and factors associated with use often diverge from correlates of cigarette smoking and consumption of other mainstream products.

Relevant Methods

To ensure that quantitative measures reflected both validated items and cultural contexts, qualitative methods were employed to explore the diversity of products used among South Asians in the USA, as well as the unique cultural influences governing use. Specifically, participants were recruited for focus groups and key informant interviews from two ethnic enclaves in the greater Chicago metropolis and Northern California (San Francisco Bay Area and Yuba City); each region was selected based on not only a high concentration of South Asians but also unique community characteristics (e.g., socioeconomic status, linguistic composition, migration history) which were distinct from other study sites. Complete details of this study can be found elsewhere [34].

Facilitators and Barriers to Recruitment of Study Participants

Recruitment of participants was necessary for two of the specific aims of the study. The first entailed the construction of focus groups which explored the diversity of products popular among South Asians in the USA; these groups were stratified by gender, generational status (immigrant vs. born in the USA), and for immigrants, length of time spent in the USA. The second also required participation of South Asians in focus groups, to conduct cognitive testing of survey item comprehension and the overall usability of the quantitative instrument. A key inclusion criterion was prior or current use of at least one cultural tobacco product to ensure practical understandings of language related to consumption. As such, purposive sampling was used to create the specific FGs necessary for each region (36 total groups), with a recruitment goal of 6–8 participants per group. Purposive sampling was used to ensure inclusion of diverse South Asian groups, including individuals of Bangladeshi, Pakistani, and Sri Lankan descent. Recruitment was conducted through invitations to participate via electronic distribution lists and presentations to South Asian community- and faith-based organizations, student clubs in academic institutions, posted flyers in areas with high traffic of South Asian individuals (e.g., ethnic markets, cultural festivals), and word-of-mouth through identified community gatekeepers, colleagues, friends, and family members. Particular emphasis was placed on disseminating information about the study to underrepresented segments of the South Asian population.

For the most part, recruitment of second generation South Asians—both male and female—was relatively simple, presumably due to an active online presence. Another group for which recruitment strategies were largely effective was male immigrants who were established in the USA for a considerable length of time. However, their female counterparts, along with recent immigrants of both genders, were difficult to recruit. In some regions (e.g., Yuba City, CA), there was simply a small subpopulation of recent immigrants from which to draw as they may have been a more dispersed and small subset of the overall South Asian population and/or did not wish to be visible due to immigration status. Female South Asians were wary to participate and required multiple modes of communication—particularly conversation by phone or in-person—to eventually become enrolled. A common concern that arose was the exclusion of males (usually a spouse or other family member) in the focus group in which a female might be participating. Some expressed apprehension about answering questions without their preferred male counterpart (e.g., husband, son, father) present, while others were skeptical about revealing potentially sensitive information in front of unrelated women in the community. For recent immigrants as a whole, there was a common fear about what information would be collected and how study findings (often involving culturally stigmatized topics) might be disseminated, particularly as it related to potential identification of individuals to the larger South Asian community as well as supervisors and faculty advisors.

Although these challenges were formidable obstacles to recruitment, the most pervasive barrier to participation was the inclusion criterion of participation, which required self-reported use of a cultural tobacco product within the past 12 months. Interested individuals often inquired about why disclosure of this behavior was necessary and if it was possible to still participate if they reported no tobacco use within the past year. Others were reluctant to label certain cultural products as tobacco, despite acknowledging it to be a constituent ingredient of items they consumed, and emphasized that it was not the same conceptually as cigarettes or cigars; this contextual interpretation precluded many from agreeing to participate. It was evident that stigma surrounding the focus of this inquiry and potential consequences related to the revelation of tobacco use to other participants and the broader community was a significant consideration for eligible South Asians to participate in this specific study.

Case #2: Enhancing Validity of a South Asian Tobacco Survey Module

Purpose and Background

As an extension of the prior study, the state of California's Tobacco-Related Disease Research Program (TRDRP) funded research to refine a survey module assessing tobacco use among South Asians to enhance its validity as a quantitative instrument as well as assess the modalities of administration which generate population-level estimates. Because random-digit-dial (RDD) and other probabilistic methods have been shown to have significant limitations, coupled with the lack of inclusion of South Asians generally in sampling for health research, the overall goal of this research was to refine a tobacco survey by enhancing its validity and usability in the field for population-level assessment of tobacco use patterns among South Asians in the USA. Complete details of this study can be found elsewhere [35].

Relevant Methods

Specifically, this study had two aims that required recruitment of South Asian participants. The first was to conduct usability and feasibility testing of the complete instrument developed in the prior study using qualitative methods (key informant interviews), while the second was to determine which modalities of survey administration (mail, online, or in-person) generated high quality data. An ancillary aim was to determine if completing surveys in paper or electronic (i.e., tablet) forms influenced completion rates and decreased respondent burden. For the first aim, South Asian participants representing varied age groups (18–65), gender, ethnic origin, and generational status were recruited to complete a paper version of the instrument and then discuss any issues or challenges they faced in doing so. Individuals were recruited through mechanisms similar to the ones employed in case #1, in order to receive a desired amount of 40 participants. The second aim entailed having individuals of South Asian descent, sampled through similar strategies, receive and complete the survey and return it to investigators. Whereas the first aim focused on qualitative data describing the process of completing the survey, the second was used to collect data characterizing patterns of tobacco use among the target population. Because of the exploratory nature of this study (and limited resources), the intent of this aim was to secure participation from 50 participants via mail and approximately 300 responses online and in-person. For mail surveys, a targeted sampling frame was procured through a marketing agency, while e-mail invitations were sent out broadly through distribution lists and membership directories for entities with large South Asian subscribers, such as community- and faith-based organizations, professional associations, student clubs, and cultural affinity groups. In-person surveillance involved time-location sampling [36] which has been shown to approximate a representative dataset from hard-to-reach populations if conducted appropriately. As this study aim was to assess proof-of-concept for tobacco surveillance—both for the sampling method and differential response between paper and electronic tablet surveys—there was no predetermined sample size that was estimated. Recruitment of participants was conducted in venues and times where large numbers and high traffic of South Asians were expected, and entailed multiple investigators approaching randomly selected individuals to determine eligibility and consent to complete the survey.

Consistent with recent research involving mail-based sampling, response rate for survey completion was extremely low (2%), despite potential respondents being sent a prefatory letter and two reminders, in addition to the survey. With respect to surveys completed via the Internet, the final sample (approximately 200) was heavily skewed toward a younger age group, presumably due to greater online access and engagement. This sample was also evenly split between foreign and USA-born individuals, although immigrants tended to have only spent a short amount of time outside of their native countries and in the USA. With respect to gender, more females than males completed the survey. These data are currently being analyzed and will be published once that process is complete.

Facilitators and Barriers to Recruitment of Study Participants

Recruitment for in-person sampling and surveillance highlighted some unique challenges in securing participation. Time-location sampling requires the random selection of an individual within a specific venue over a certain time frame. For this study, this involved approaching a random individual, confirming eligibility, providing informed consent, and providing a survey to be completed in the field. This process required a considerable amount of time, which was a barrier for many participants, despite eligibility and interest. The original $20 stipend provided for participation was not seen as sufficient for the opportunity cost and had to be doubled to $40 in order to substantially increase the sample by at least fourfold.

Moreover, for interested participants, the topic of the study (tobacco use patterns) often dissuaded further involvement, despite indicating that information from nonusers was equally important for the purposes of surveillance. For this study, over 500 individuals were contacted for potential participation (over multiple dates/times/venues). It was clearly evident that, depending on demographic characteristics, cultural concordance of interviewer and respondent was a key influence on whether individuals agreed to consent and ultimately complete the survey. This was especially true for gender, as females and their male acquaintances tended to be more hesitant or skeptical when approached by a male interviewer; even in situations where women exhibited interest, the accompanying man would intercede, ask specific questions about the study and/or extent of participation, and often overrule any further progress on participation. Such preferences were also seen for religion (particularly for Muslims and Sikhs, with amplified influence of gender disconcordance) and South Asian region of origin (often conveyed by specific attire/accessories or linguistic introduction). Such affinities were especially observed for older adults, but did play a considerable role for community members who seemed more junior in age, especially among immigrants.

A final barrier in recruitment was the perceived burden put on the respondent for participation. For those who wished to complete the instrument on paper, the number of survey pages was a key barrier, despite assurances that not all questions would be applicable depending on the use (or lack thereof) of specific products. On the other hand, navigating the survey on an electronic tablet (Apple iPad) was complex for some respondents, with many having difficulty with functions related to scrolling, advancing and backtracking, and submitting answers on open-ended text fields. Not surprisingly, younger participants preferred the electronic tablet, whereas their senior counterparts requested paper surveys, often requiring assistance from interviewers with instructions and interpretations/translations.

Case #3: Real-Time Data Capture of Online Epidemiologic Data Among South Asians

Purpose and Background

The South Asian Community Health Initiative (CHI) study was a pilot study funded by Spectrum, the Stanford Center for Clinical and Translational Research and Education at Stanford University School of Medicine. The overall purpose of this study was to better understand how to engage South Asians in health research. South Asians are one of the largest and fastest growing Asian American subgroups in the San Francisco Bay Area. Health disparities are prevalent in the South Asian population, as they are disproportionately affected by cardiovascular disease and its risk factors, including high incidence of obesity, high blood pressure, high cholesterol, and diabetes. The capture of research data in real-time, referred to as ecologic momentary assessment (EMA), is an increasingly common method used in clinical psychology and is now facilitated by the use of mobile devices. However, despite the potential of these technologies and methods for data validity and efficiency, practical evidence regarding their feasibility and acceptability for health-related research is largely lacking for minority populations, particularly among South Asians and other English-proficient Asian American subgroups.

Relevant Methods

The South Asian CHI study aimed to (1) identify health needs and concerns and preferences for or barriers to participating in health research, (2) identify potential ways to integrate technology to support participation, and (3) test the feasibility of real-time online epidemiologic data collection via EMA. In addition, as a pilot study, a key objective was to build inroads to the growing South Asian community in the San Francisco Greater Bay Area. For the first and second aims, the goal was to recruit 12–24 participants, between the ages of 30 and 60 years, for two focus groups (one male and one female). For the third aim, the target enrollment was 32 adults, 18 years and older, with balanced samples of men and women, for a series of online surveys using an EMA approach.

Several outreach strategies were used to recruit participants, including staff outreach in neighborhoods with a high concentration of South Asians (e.g., in-person recruitment by staff at famers markets, local subway stations), support from social, cultural, professional, and religious community organizations (e.g., mention of the study at planned events and posting of study information on community boards and newsletters), Internet/social media (e.g., Craigslist, Facebook), and referrals from participants, study staff, and community members. A study website, targeted flyers, and informational text were developed to disseminate study information through social media postings as well as advertisements (e.g., community and religious center newsletters, Craigslist). Focus group participants were given a $40 Amazon gift card for their participation; EMA participants were given $1 for each brief online survey completed (up to 12) and $10 for a user experience survey at the end, for a total of up to $22 for their participation. For the qualitative (focus group) component, there was a 36% response rate (50% for males; 24% for females); response rates were calculated as percent of those who participated among those who expressed interest and were eligible. For the EMA component, there was a 45% response rate (48% for males; 42% for females).

Facilitators and Barriers to Recruitment

In the qualitative phase of study, the most success in identifying large numbers of potential participants came from staff outreach ($n = 25$), followed by referrals ($n = 16$), and outreach via community organizations ($n = 11$), with very little yield from postings on social media or the Internet ($n = 6$). Outreach through community organizations resulted in the highest proportion of participants of those who expressed interest, with 5 of 11 participating in the focus groups. Key factors facilitating participation in research included having (1) recruitment personnel reflect community and connect to target population, (2) active (in-person, telephone) rather than passive recruitment (flyers; online posts), (3) credibility and trustworthiness of funder/host organization (related to effectiveness of "messenger"), and (4) relevance of topic to individual, family, and/or community. For example, participants noted that they participated "because of [coordinator]. When I spoke to her and she is from Mumbai, so I was like okay and I start talked and she is also from […], so we are from same place and I used to come close by where she lived in Mumbai, so it sounded safe" (female focus group participant). Others really appreciated the active recruitment strategy, "The moment we sent the email, we got a prompt response. So that kind of made the difference" (male focus group participant); "[the coordinator] called me a few times, she sent out reminders, she sent out detailed emails" (male focus group participant). Credibility of the study was assessed by the credibility of the messenger/recruiter, such that "Some mails used to come but I discarded it because credibility was missing. For me it was most important that it came from [major Indian University] alumni association group. So immediate[ly] I knew that it is not some bogus…" (male focus group participant). Many also said they were motivated to participate because the study was about their community and a topic that was personally relevant to them: "I am [participating] because it was South Asian that was the only reason" (female focus group participant); "I think one of the things is that, it's been for South Asian community. We belong to that community and I thought that I have some input from my side to give in this, in this study." (male focus group participant); "yeah. So if it is something personal that I have it or if my family has history of it. So probably I will jump on it." (male focus group participant).

For the EMA survey phase, staff outreach was the most effective strategy to identify potential participants (*n* = 25), followed by a pool of prior study participants who had expressed interest in being contacted for future studies (*n* = 21). Other strategies procuring participation included invitations via social media or Internet (*n* = 19), community organizations (*n* = 13), and referrals (*n* = 10). Again, community organizations resulted in the highest proportion of participants of those who expressed interest, with 8 of 13 participating; referrals also had a high yield, with 6 out of 10 participating. While more websites and social media pages posted study materials/information, the final yield of participants was not high.

For both components, community organizations and referrals were the most successful strategies for recruiting participants. One challenge with recruiting via community organizations is that it was very resource intensive. For the focus groups, 44 organizations were contacted, averaging two or three e-mails and/or four or more calls per organization to introduce the study and request help with recruiting participants. This resulted in 11 people who expressed interest and five who participated in the study. Similarly, for the EMA component, communication with 37 organizations resulted in 13 people who expressed interest and 8 who participated. The limited success with this strategy was due to the stronger research collaboration with a large community organization that was willing to assign their staff with recruitment-related tasks (e.g., sharing flyers, posters).

While study staff outreach identified many potential participants, overall, it was not as successful as some of the other recruitment strategies used in this study, as the final yield of participants was lower than from other approaches and it required substantial time and resources to be out in the community.

Barriers to participation in research predominantly included logistical factors such as travel distance, time, ease of protocol, frequency of visits, and duration of study. Factors that were thought of as conditional included appropriateness of topic (including associated stigma) based on demographic, legal, and social/cultural background, invasiveness of research, anonymity and uses of identifiable data, as well as social and physical difficulty and permanence of behavioral change desired. For example, some of the logistical barriers reported by participants include the following: "it was matter of figuring out whether times and everything else is going to work: (female focus group participant); "Location and time as well" (male focus group participant). Other factors seemed to be dependent on the study context. Studies on stigmatized topics were identified as recruitment barriers, "There are certain sections of our community, if I have a cancer, there are certain sections of our community will treat me as 'Paraya' (Hindi word for 'who is not yours') the moment when they know I have Cancer" (male focus group participant). Others identified difficulty in changing outcome of interest and transparency of benefit as barriers: "it all depends on whether it's a lifestyle change or a behavioral change or diet change, it all depends what kind of change we are talking about, what's the time factor involved in bringing about the change and is that person, let's say in this case me if I am happy to go through that change, when I am going to see the positive aspects of that. Change getting reflected and benefiting me" (female focus group participant). Additional barriers included study protocols requiring participants to partake in invasive procedures, including colonoscopy, blood draws, or provision of salivary samples as well as studies that may require changes to diets and medication use.

Case #4: Barriers to Colorectal Cancer Screening in South Asian Communities

Purpose and Background

The overall goal of this project was to better understand low rates of colorectal cancer (CRC) screening among South

Asians in the USA. Specifically, a community-based participatory research study—funded by the Centers for Disease Control and Prevention—was conducted to better understand South Asians' beliefs about CRC screening and what causes CRC.

Relevant Methods

In a qualitative study involving focus groups, data was gathered from participants regarding the perceived risks and barriers to screening, as well as advising on messages the community needed to hear about CRC screening. With respect to the need for South Asian community participation, the study sample included eight focus groups of about 6–8 participants each, specifically of Asian Indian and Bangladeshi descent who were over 49 years of age. Participants were divided into focus groups based on gender and ethnicity and were recruited mainly through community-based and faith-based organizations. This targeted recruitment resulted in a total of 53 participants, split into two Asian Indian male focus groups, two Asian Indian female focus groups, two Bangladeshi male focus groups, and two Bangladeshi female focus groups.

Facilitators and Barriers to Recruitment

Asian Indians were readily available for recruitment through the help of a local established community-based organization (CBO) with multiple sites in the San Francisco Bay Area; organizational members were familiar with ongoing research in the region and study investigators. Recruiting Bangladeshis proved to be much more challenging on two fronts: logistics and gender. Originally, a parallel effort to recruit Bangladeshis was employed by partnering with a local CBO which was a small nonprofit entity in the South San Francisco Bay Area. Several student researchers went to a Bangladeshi Independence Day cultural festival hosted by the association to recruit for the first focus group. Even though they received an ample number of signups, only four men actually came to the focus group. While calling those who had signed up to confirm a date and time, the students noted that many of these individuals were reluctant to follow through. Specifically, many of the potential participants demonstrated general skepticism about the research and felt inconvenienced by the drive to another location to meet, especially with the focus groups being held on the weekends. This seemed to be a particular concern for Bangladeshi women, and some of whom mentioned their husbands would need to drive them. Furthermore, while the recruitment happened at a cultural event, the first focus group was held at a mosque. This may have caused some reluctance to participate, since those attending the cultural event may not have been religious enough to feel comfortable attending a mosque. It may have also been that those attending the earlier event may not have been Muslim either, and some may not have wanted to affiliate themselves with an environment that did not match their religious identity.

Such organizational challenges were not encountered with recruitment through the Indian-serving CBO, which may be related to organizational differences between CBOs, including infrastructure and visible presence in the community. While the Indian-serving CBO had two large facilities, multiple rooms, and a familiarity with events discussing health, the smaller Bangladeshi CBO had no physical location or precedence for such discussions. The recruiting of and focus groups with Asian Indians would both take place at CBO sites, while the two activities would be separate for Bangladeshis. Instead, the Bangladeshi CBO functioned more as a virtual network of Bangladeshis that primarily communicated through social media and e-mail without a physical space. Although the connection to the organization originated through a Bangladeshi physician who had worked with the study's host academic institution in the past, within the first couple of months, the researchers experienced difficulties in coordinating with the CBO. With no tangible space, the Bangladeshi-serving CBO as a full recruitment partner fell through, although they continued participating on the study's advisory board.

With the lack of success with this outreach strategy, recruitment efforts were subsequently focused on faith-based outreach in mosques to recruit Bangladeshis, since Islam is the predominant religious affiliation of this population. This also proved to be difficult in many ways. As opposed to the Asian Indian CBO having predominantly Asian Indian members, including a sizable population of seniors above 50 years of age, mosques included members of multiple ethnicities and age groups, making it difficult for student researchers to correctly identify and approach the target populations required for this study. When student researchers went to a South Bay mosque, there were only two Bangladeshi signups among the 15 to 20 other South Asian signups. Therefore, finding a mosque with a significant Bangladeshi population also proved to be difficult, since this South Asian subgroup was not as large as Asian Indians or Pakistanis nor predominantly present at any one mosque; therefore, no focus group resulted for the initial faith-based targeted outreach.

The team shifted toward using personal connections with prominent members in the Bangladeshi community to aid with recruitment, since direct interactions between researchers and community members were met with hesitation and presumed mistrust. A project consultant contacted an Imam (religious leader) in the South Bay Area whom he knew through a sustained relationship from a prior research collaboration. With his help, including making an announcement in the Jummah (Friday) prayer, and the aid of another Bangladeshi man at the mosque organizing potential participants, the team finally secured the participation necessary for the successful execution of a second male focus group. These efforts were bolstered by the presence of student researchers who were linguistically and culturally concordant.

Despite these successes with males, neither the Independence Day event nor the mosque outreaches were successful initially in recruiting Bangladeshi women. Women seemed to be not receptive nor were observed in areas where the researchers were present. They also exhibited hesitation when male student researchers approached them for recruitment. For those who did provide contact information, upon calling them to confirm participation, many stated they would not go anywhere or share any information without their husbands present. The team then had to leverage relationships with a female Indian Muslim medical student familiar with local mosques and a female Bangladeshi physician on the project advisory board to form the women's focus group. Through these cultural gatekeepers, it was conveyed that the sensitivity of study topic, coupled with discordant research personnel (specifically gender and faith), was a considerable barrier for participation and candor.

In order to meet the requisite number of female focus groups, researchers also had to travel further, going from San Francisco Bay Area to communities within the Sacramento Metropolitan Area to identify a population of Bangladeshi women. After reassurance from their personal connections and their guaranteed presence at the focus group, the women followed through. The focus group, held at a local mosque in Davis, was facilitated by the male project consultant with the assistance of a female principal investigator, the aforementioned female medical student, and two male student researchers present. The conversation seemed comfortable and women did not seem shy with men on the research team, especially when introductions and side conversations were held in their native language, Bengali/Bangla.

In contrast, women in the second focus group requested no men present and strongly expressed a desire to have the female Bangladeshi physician who recruited them into the study be the facilitator for the group. In meeting their wishes, and in order to build trust and ensure candor, the physician was trained in qualitative facilitation. The focus group was held at a private home. Therefore, while Bangladeshi men were able to be effectively recruited at an institutional level, securing women participants were highly dependent on outreach conducted predominantly through trusted interpersonal connections. It was clear that both men and women preferred communication with and/or the presence of someone they knew in order for them to trust unfamiliar members of a research team (Table 1).

Discussion

The featured case studies provide practical insight into the unique challenges in recruitment of South Asians for health research in the USA. Consistent with the literature examining lack of inclusion of Asian subgroups, barriers to recruitment and retention of participants revolved around competing priorities, confusion and/or skepticism about study purpose and protocols, perceived stigma surrounding research topics, and influences related to family, community, and cultural preferences and norms. Overcoming such obstacles requires a deliberate, sustained, and community-oriented approach, ensuring that potential participants are fully informed and supported within broader social and cultural contexts. Based on our experience and reflective analysis, we enumerate the following key recommendations to optimize recruitment and participation of South Asians in health disparities research studies in the USA.

- Effective approaches

  - Active recruitment: Activities include culturally appropriate presentations about relevant studies at community-based organizations and other social forums, targeted communications using personalized messaging via phone and e-mail, and advertisement of incentive appropriate for social and economic context of target population.
  - Cultural research brokers: Individuals actively engaged in recruitment should not only visibly and linguistically represent diverse dimensions of community but also possess credentials held in high regard by members of target community (e.g., medical professionals, possession of advanced degrees).
  - Trusted sources of information: Engagement of community leaders (not research personnel) and organizations is pivotal for assuming key roles and capacities for recruitment, including training for disseminating information and addressing specific questions about study purpose and need for participation to be conveyed to the target population. Such leaders should be highlighted as contacts in recruitment materials.

- Promising strategies

  - Authentic collaborations: Researchers should develop and sustain sincere partnerships that are mutually beneficial and require attention and engagement irrespective of whether studies needing participants are in process or being developed.
  - Community-based organizations and leaders as messengers: Study protocols and project budgets should support active roles and responsibilities for community-based organizations and leaders, including relevant trainings and certifications and compensation for time and effort.
  - Dissemination of research findings and studies through cultural channels: Investigators must make concerted efforts to not only disseminate findings from studies to those participants and community members who made the research possible but also to generally apprise these

Table 1 Featured Studies in Case Study Series

Barriers to participation	Case #1: Development of a South Asian Tobacco Use Module	Case #2: Enhancing Validity of a South Asian Tobacco Survey Module	Case #3: Real-time Data Capture of Online Epidemiologic Data among South Asians	Case #4: Colorectal Cancer Screening in South Asian Communities
Gender issues (women requiring husbands for presence in focus groups and transportation, women expressing hesitation when approached by male researchers, women skeptical about revealing sensitive information in front of community members)	✓	✓	✓	✓
Logistical issues (location, travel time, difficulty with recruitment at religious sites, i.e., mosques having other ethnicities other than South Asian or religious sites where women and men are separated)		✓	✓	✓
Stigmatized topics resulting in nonparticipation (not discussed commonly in the community, fear of potential identification of participants to larger community, skepticism regarding benefits of research)	✓	✓	✓	
Ineffective passive recruitment (flyers, invitations through e-mail distribution lists, weblinks)	✓	✓	✓	✓
Less established community-based organizations with no physical locations or organizations with no precedence for discussion on health				✓
Facilitators to participation				
Partners (well-established community-based/religious-based organizations; opportunities for active outreach i.e., having trusted voices such as officials in CBOs to advertise the research)		✓		✓
Research team (ethnically, linguistically, or culturally concordant)	✓	✓	✓	✓
"Cultural gatekeepers" providing credibility to the study (e.g., having an Imam announce the research at a *Jummah* prayer, having a culturally concordant physician reach out to others, having colleagues personally e-mail potential participants)	✓		✓	✓
Gender issues (having female "cultural gatekeepers" to recruit female participants, e.g., having South Asian Muslim women recruit Bangladeshi women)				✓
Acceptable financial incentive for participation (e.g., suitable amount, gift cards, stipends)		✓		✓

✓ Indicated presence of barrier or facilitator to participation in featured study

stakeholders about current and emerging research of interest and importance to their health.

The following further details the effective processes for recruitment of South Asian participants, which were employed within and across the featured studies, followed by a expanded description of promising strategies based on the authors collective experiences and familiarity with the literature on South Asian health disparities.

Effective Approaches

Active Recruitment

Across all four studies, passive recruitment for participation (e.g., posted flyers, web links, generic invitations through distribution lists) proved to be ineffective. Even if the initial notice was of interest, many individuals simply forgot at a later time or misplaced study details and/or contact information. In contrast, active outreach and communication strategies resulted in securing most of the participants in each study. For example, a brief presentation by investigators and student researchers involved in the Colorectal Cancer Screening Study (case #4) given at the Indian-serving CBO, followed by a question-and-answer session, generated interest from many eventual participants; many audience members wished there were more such events that articulated the importance of community participation in particular research studies. Such active strategies were strengthened when diversity of gender, languages, and faiths were represented on the study teams. For both tobacco-related studies (case #1 and case #2), targeted e-mails to individuals identified by colleagues, friends, and family members proved beneficial. Such personalized invitations, commonly coupled with a subsequent phone and/or in-person conversation, facilitated a connection between researcher and potential participant taking into account preferences and limitations of all parties and enabled resolution of any confusions or apprehensions related to study involvement. This open line of communication often allowed for further recruitment of additional participants to occur via word-of-mouth to others potentially eligible in family or social networks. Across all studies, a visible and engaged presence with target study populations was essential to securing participation; posting of study details and generic advertisements did not garner substantial response. However, caution should be exercised when foci of research involve topics sensitive to particular venues and contexts, such as illicit or scrutinized behavior in conservative settings or among subgroups for which stigma may be attached; such research studies may benefit from other strategies detailed later.

Tangentially, an appropriate incentive (financial or otherwise) was also deemed important for consideration of opportunity costs related to participation (case #2 and case #4). For instance, the original value of money or gift cards was said to be insufficient for the extent of engagement required, given the cost-of-living in the San Francisco Bay Area or greater Chicago metropolitan area. The dedicated time required to fully participate in research was also a considerable factor. In the South Asian CHI study (case #3), it was found that brief surveys or other short activities that participants can complete right away may positively influence participation. In order for active recruitment strategies to be effective, all such considerations must be taken into account.

Cultural Research Brokers

A pivotal element of a successful active recruitment strategy detailed prior is the use of cultural research brokers for outreach and enrollment of participants. In the health disparities literature, a common practice is the use of patient navigators to optimize equal access and quality in the health care system [37]. The premise of such an effort is that linguistic and cultural factors impeding communication, trust, and compliance among diverse populations may be mitigated if advocates representing varying patient backgrounds and perspectives are involved in coordination of care, playing a socially supportive role, and maximizing efficacy of treatment [38].

A similar process was seen with respect to study personnel who were effective in securing participation in each of these studies. Initially, investigators for all studies presumed that having a South Asian individual—irrespective of gender, faith, generational status, and perceived age—would be sufficient for connecting with members of the community. However, it was quickly realized that access to and communication with researchers representing many dimensions of South Asian identity was necessary for both random and purposive sampling. This was most clearly evident in feedback from individuals enrolled in the South Asian CHI study, who overwhelmingly agreed that the outreach coordinator was the reason they agreed to participate (case #3). As an immigrant, the coordinator was able to dispel any myths about unethical practices and/or ulterior motives in the study (which was perceived by many participants as commonplace in South Asia), accurately and contextually describe the purpose of this research, and convincingly articulate the need for community participation, including from underrepresented South Asian subgroups. A similar situation presented itself in the Colorectal Cancer Screening study, for which recruitment of female Bangladeshis for focus groups was extremely challenging. However, once a community advisory board member, who was a Bangladeshi medical doctor and a South Asian medical student (whose family was well connected to the local South Asian Muslim community), began to actively recruit, study investigators were able to ensure that the requisite number of focus groups involving Bangladeshis were conducted (case #4). Participants conveyed that the dual “credentials” of this individual being from the community as well as qualifications as physician/medical student provided the credibility needed to join this particular study especially when sustained and substantive efforts in communication by these gatekeepers were made.

A final illustration of cultural concordance was found in the probabilistic time-location sampling process employed in the Tobacco Survey Module Validity study (case #2). In this case, individuals were randomly selected and those eligible were invited to participate. Those agreeing to complete surveys were approached by research staff who visually or verbally represented the background of the participant. For instance, women were more likely to participate if approached by a female, those subscribing to a certain faith tended to accept the invitation if the interviewer was of the same religion (often exemplified by external attire, such as a turban for Sikhs, or names suggesting a Muslim or Hindu background), and use of in-language greetings distinguishing regional dialects or colloquial salutations positively influenced response rates. Subsequent sampling events were more successful if the team of surveyors was diverse in terms of gender, faith, language, and perceived age/generational status.

These diverse illustrations demonstrate that simply ensuring research personnel who exhibit racial/ethnic overlap with the target population is not sufficient for effective community outreach and participant recruitment. Rather, ensuring that researchers interacting with the community-of-interest are concordant with respect to other dimensions of identity—in this case, gender, faith, generational status, and age—are paramount to recruitment of South Asians in health research studies. Furthermore, in order for such individuals to be effective, they must not only be trained in salient research protocols but also be able to convey the study purpose and need for certain forms of participation in manner contextually comprehensible by members of the target population.

Trusted Source of Information

A third approach shown to optimize recruitment involved the source from which information about research studies was being presented. In some instances, the use of aforementioned diverse cultural brokers was not sufficient to fill enrollment targets, despite the breadth of outreach activities employed by research personnel. An alternative recruitment mechanism proved to be an effective complementary strategy. These efforts revolved around highlighting the collaboration with and approval of research conveyed by established and trusted community organizations, in parallel with a visible mention of the funding organization, entity conducting the research, and/or investigators involved. Often, researchers tend to highlight information that hold value to them with respect to affiliation and funding; however, most community members tended to be more interested in collaborations with community-based entities, particularly when their leaders encouraged participation through written or verbal invitations.

A nuanced illustration can be found in the Tobacco Survey Development study (case #1). One study site in Northern California contained a large number of South Asians from the state of Punjab who overwhelmingly subscribe to the Sikh faith; this region was purposely selected to ensure inclusion of underrepresented subgroups. However, based on this demographic profile, investigators recognized that potential participants may be hesitant to admit to or discuss tobacco use given strict religious prohibitions, particularly among women. Despite multiple efforts employing active recruitment with cultural brokers, constructing a complete focus group over a considerable period of time proved challenging. Through a prior research collaboration, investigators sought the guidance of a former executive board member of a highly reputable faith-based organization (*gurdwara*) functioning in the region. She suggested that the current leader not only make a brief presentation to its congregation but also follow up with a personalized e-mail validating the purpose of the study and stressing the need for participation. This leader also provided a religious and spiritual context for which understanding tobacco use among South Asians was important. Based on these convincing pleas, focus groups involving both men and women became quickly filled. A parallel effort was similarly effective involving direct outreach and invitations sent out by the Indian-serving CBO in the San Francisco Bay Area for all of the featured studies. An enhanced capability for recruitment included training selected staff and leaders in human subject protection, per National Institute of Health (NIH) guidelines, and thus the CBO was able to screen and enroll individuals into research studies (case #3). It should be noted that inclusion of funding sources and academic/research institution is not irrelevant, as some participants stressed that reputable sponsors and host organizations strongly influenced their decision to participate. However, it was equally important to prioritize locally recognized community or cultural partners in all outreach materials, recruitment activities, and word-of-mouth dissemination.

Promising Strategies

Authentic Collaborations

Due to limitations of time and resources, coupled with competing priorities, it is commonplace that academic and scientific communities often attempt to engage in collaborations on an agenda and timeline of importance to researchers without taking into account an accurate and in-depth understanding of community contexts, priorities, and challenges [39, 40]. Without a systematic emphasis on long-term and sustained relationships, the authenticity of partnership needed for community participation and representation may be compromised [41].

Admittedly, many of the featured studies did not employ such approaches and as a result, it was challenging if not impossible to secure the required or preferred number of participants, particularly among underrepresented subgroups. However, because each of these studies focused on a particular element of health among South Asians in the USA and overlapped or were close to each other in time, an organic relationship was formed and sustained among leaders of certain CBOs. Organizational representatives and members became familiar with local investigators and subsequently developed sustained channels of communication. This has resulted in invitations from diverse community groups to conduct educational and substantive workshops and highlight relevant and ongoing research activities being conducted by investigators and their affiliated organizations. These dynamics facilitated the maintenance of a mutually beneficial partnership, enabling more feasible/successful recruitment of South

Asians in future health studies. This experience stresses the importance of developing sustained and authentic relationships *irrespective of whether a study is in progress*. In the case of recruitment of South Asians in health research, dedicated time and effort to development and maintenance of authentic organizational and community collaborations is essential.

Community-Based Organizations and Leaders as Messengers

It was evident that cultural brokers played a pivotal role in securing participation of individuals of diverse South Asian backgrounds. Many of these individuals were part of the research team and successes in recruitment, as observed and documented, were largely due to cultural affinity and connection with study samples. In select circumstances, collaborating organizational leaders and community gatekeepers were put in positions where they served as ad hoc study recruiters. In their presumed position of trust and credibility, it was clear that they possessed the contextual capacity and influence in securing participation for diverse study topics and research designs. This observation is consistent with broader principles of community-based participatory research [42].

For health research involving South Asian participants, community-based organizations serve significant social, cultural, and developmental functions. As such, they hold tremendous value for increasing awareness and targeted outreach among diverse segments of the South Asian community [43]. Based on observations from these studies, providing financial resources and other forms of support to the organization for purposes of outreach and recruitment holds great promise, especially for segments of the South Asian population not easily reached through in-person and/or online methods. Such efforts may be bolstered if community organizations and leaders are familiarized with relevant information about study purpose, protocols, and a summary of risks and benefits, as well as basic training in human subjects protocols (if engaging in actual enrollment of participants). Although perhaps not a high priority benefit for collaboration, certification from bodies such as the NIH enables development of research infrastructure for CBOs. Such increased capacity may not only lead to increased and enhanced partnerships with academic/research institutions but also empower these CBOs to embark on their own studies with their constituent groups.

Dissemination of Research Findings and Studies Through Cultural Channels

Many academic and scientific researchers prioritize the dissemination of study findings in peer-reviewed outlets, such as journals and conference abstracts [44]. It has been argued that it is unethical to not provide timely and accurate information to the community without which research could not have been conducted [45]. Unsurprisingly, journal articles or conference abstracts are not the most visible or preferred channels of communication for community members to receive health-related information.

In the experience of conducting all of these studies, it was clear that many participants wanted to know the eventual results of the studies they participated in, be it about the harms of cultural tobacco use, the ease of online data collection, or the importance of colorectal cancer screening. There were multiple questions about the relevance and accuracy of information community members had received through multiple channels and wanted to rely on those who they had made contact with and developed relationships through the process of study participation. For the most recent study of the four presented, both organizational leaders and individual community members strongly requested presentations in community forums about the importance of colorectal cancer screening, accuracy of guidelines and modalities they were exposed to, and mechanisms of access to preventive care. It was evident that community members were eager to increase their own awareness and pass on valid information to their families and peer groups, as well as the broader community; this process of community-based dissemination is currently underway for this study including development of low literacy and in language materials addressing concerns raised in the study. It is clear that researchers, especially those who have engaged in collaborations with CBOs and at-risk populations, have a responsibility to ensure that research findings are presented in appropriate cultural channels and in a manner that is comprehensible by these population groups. In addition, this reciprocity of data collection and community dissemination results in a greater likelihood of better participation in future studies. Because these multiple studies had investigators in common, as well as overlapping buy-in from specific organizations and individuals, the impact on recruitment and participation was clearly observed in those occurring more recently. For health research involving South Asians in the USA, ensuring that resources, time, and personnel are dedicated to the process of community-level dissemination of research findings and study proposals is a key component in optimizing enrollment.

Conclusion

Within the larger framework of health disparities research, understanding differential patterns of disease and risk factors by meaningful subgroups is paramount to achieving health equity. This case study series provides insight about the challenges posed in recruiting South Asians, a uniquely diverse subset of the broader Asian American population, into studies with different aims and designs. However, there were common barriers found in securing participation across all featured studies. Moreover, investigators involved in these studies were able to employ specific strategies to overcome contextual obstacles and explore promising practices based on community feedback and ancillary efforts. A review of the literature suggests that sufficient, if not optimal, recruitment of South Asians in the USA in health-related studies remains a considerable issue worthy of attention. Researchers must take into account the complexity of building relationships and trust with South Asians, including the CBOs that represent their interests. Study designs should dedicate time, resources, and personnel to these pivotal processes. Agencies funding health disparities research should also exhibit flexibility in providing support for activities that enable community engagement, without solely prioritizing output of value to researchers and their affiliated institutions. A deliberate, sustained, and authentic effort holds immense value in ensuring that understudied and at-risk populations, such as the South Asian population in the USA, are included and engaged in research that foremost benefits them.

Acknowledgments The authors wish to thank Hibah Mahmood, Sadaf Sareshwala, and Scarlett Lin Gomez for their input, feedback, and other contributions to this manuscript.

Compliance with Ethical Standards

Funding The Development of a South Asian Tobacco Use Module Study was funded by a Research Supplement to Promote Diversity in Health-Related Research by National Cancer Institute of the National Institutes of Health (Grant: U01 CA 114640). The Enhancing Validity of a South Asian Tobacco Survey Module Study was funded as a Postdoctoral Fellowship Award by the state of California's Tobacco-Related Disease Program (Grant: 19FT-0175). The Barriers to Colorectal Cancer Screening in South Asian Communities was funded by the Centers for Disease Control and Prevention as a Special Interest Project (Grant: U48DP004998). The Real-time Data Capture of Online Epidemiologic Data among South Asians (or South Asian CHI) was funded by Stanford University's Spectrum Pilot Seed Grants for Population Health Sciences (Grant: UL1 TR001085), with additional support from the California Breast Cancer Research Program (Grant: 17UB-8602). All the contents provided here represent the viewpoints of the authors and not necessarily those of the aforementioned funding sources.

Conflicts of Interest The authors declare that they have no conflict of interest..

Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all individual participants included in these studies.

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