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Study Design

Retaining Hispanics: Lessons From the Hispanic Community Health Study/Study of Latinos

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We aimed to examine the retention of Hispanics/Latinos participating in the Hispanic Community Health Study/Study of Latinos (HCHS/SOL), a prospective cohort study of 16,415 adults in 4 US cities who were enrolled between 2008 and 2011. We summarized retention strategies and examined contact, response, and participation rates over 5 years of annual follow-up interviews. We then evaluated motivations for participation and satisfaction with retention efforts among participants who completed a second in-person interview approximately 6 years after their baseline interview. Finally, we conducted logistic regression analyses estimating associations of demographic, health, and interview characteristics at study visit 1 (baseline) with participation, high motivation, and high satisfaction at visit 2. Across 5 years, the HCHS/SOL maintained contact, response, and participation rates over 80%. The most difficult Hispanic/Latino populations to retain included young, single, US-born males with less than a high school education. At visit 2, we found high rates of motivation and satisfaction. HCHS/SOL participants primarily sought to help their community and learn more about their health. High rates of retention of Hispanics/Latinos can be facilitated through the employment of bilingual/bicultural staff and the development of culturally tailored retention materials.

cohort studies; follow-up; Hispanics/Latinos; longitudinal population-based studies; recruitment; retention

Abbreviations: AFU, annual follow-up; GED, General Educational Development; HCHS/SOL, Hispanic Community Health Study/Study of Latinos; MHF, mental health functioning; PFQ, Participant Feedback Questionnaire; PHF, physical health functioning.

In 2016, the US Hispanic/Latino population reached 58 million—18% of the US population (1). Their participation in research is essential to ensure that US population health data accurately reflect their lives and experiences. The Hispanic Community Health Study/Study of Latinos (HCHS/SOL) is the most comprehensive study of Hispanic/Latino health in the United States carried out to date (2). HCHS/SOL provides a rare opportunity to understand what motivates Hispanic adults to participate in large prospective cohort studies and the strategies that can be used to successfully promote their retention.

Noting the relative lack of studies pertaining to the recruitment and retention of Hispanics/Latinos, authors of recent systematic reviews have highlighted several common barriers

to participation in research and strategies for facilitating participation and retention (3–5). Barriers to research participation include mistrust of researchers; logistical challenges, such as lack of transportation or child care; competing demands from family, work, or school; fears of physical discomfort or injury; concerns regarding the privacy and confidentiality of medical information, especially for stigmatized conditions; and, in one study focused on Hispanics/Latinos (6), fears that research participation might result in deportation.

Strategies for facilitating recruitment and retention focus on addressing these barriers (3–5). Researchers build trust by seeking community involvement in the study design and communication strategies, hiring culturally/

linguistically congruent staff familiar with the participants' communities, and tailoring communications to the educational levels and backgrounds of participants. Additionally, researchers can take steps to minimize the financial costs of participation, improve the logistical ease of participation, lower the psychosocial and physical risks of participation, provide direct benefits for participation, and articulate the altruistic benefits of participation.

In this study, we aimed to obtain insight into how to engage and maintain high response rates in Hispanic/Latino populations. We describe the retention strategies used in HCHS/SOL, identify the characteristics of participants with continuous participation in annual follow-up (AFU) interviews, evaluate participants' motivations for participation and the characteristics of those very motivated to continue participation, and evaluate participants' satisfaction with participation and the characteristics of those who were very satisfied with multiple aspects of the study.

METHODS

Data

Between 2008 and 2011, a total of 16,415 noninstitutionalized self-identified Hispanic/Latino adults aged 18–74 years were enrolled in HCHS/SOL at the time of screening. Participants were randomly selected from households at 4 US field centers (Bronx, New York; Chicago, Illinois; Miami, Florida; and San Diego, California) to complete a baseline clinical examination (visit 1) that included comprehensive biological, behavioral, and sociodemographic assessments. Visit 1 lasted an average of 6.6 hours. Previous publications provide details on the study design, sampling approach, and recruitment strategies of HCHS/SOL (2, 7, 8).

Following completion of visit 1, participants were contacted every 12 months for a 30-minute AFU interview to document general self-reported health and medical events that had occurred since the baseline visit or the previous AFU. AFUs were conducted primarily via telephone in the participant's preferred language (Spanish or English). All participants who were alive and noninstitutionalized and had not withdrawn consent to participate in future studies were eligible to complete an AFU during a 3-month window before the anniversary of their baseline visit and a 3-month window after the anniversary. If a participant was institutionalized or not able to complete an AFU because of cognitive impairment, a designated proxy respondent (typically a family member) was asked to complete the AFU on the participant's behalf. Our analysis of retention in the HCHS/SOL focused on the first 5 years of AFU interviews (AFU1–AFU5).

An average of 6 years after the completion of visit 1, participants who were alive and noninstitutionalized and had not previously withdrawn consent to be contacted for future studies ($n = 15,576$) were invited to participate in a second clinical examination (called visit 2). Facilitated by AFU interviews, the retention rate at visit 2 was 81%. A total of 1,224 participants were administratively excluded from participating in visit 2 because they had relocated outside of the United States or had moved more than 100 miles

(160 km) from the nearest HCHS/SOL field center. Between October 1, 2014, and December 31, 2015, the Participant Feedback Questionnaire (PFQ) was included in the visit 2 protocol and administered to *all* participants completing visit 2 during this time period. The questionnaire, completed by 98% ($n = 5,367$) of those asked, inquired about participants' motivations to participate and their satisfaction with various aspects of the study.

After exclusion of observations with missing data on the independent variables described below, analytical samples for this analysis consisted of 16,243 participants at baseline who were eligible for an AFU, 15,930 participants who were eligible for participation in AFU1–AFU5, and 5,227 participants who had completed the PFQ at visit 2.

Measures

Our analysis of retention focused on 3 outcome measures—AFU persistence, visit 2 motivation, and visit 2 satisfaction. We considered associations of these outcomes with 3 sets of independent variables measured at visit 1—demographic characteristics, health characteristics, and interview characteristics. For detailed information about HCHS/SOL and links to all questionnaires, please see the HCHS/SOL website (<https://sites.csc.unc.edu/hchs/>).

AFU participation and persistence. At each AFU, participants were identified as contacted (yes/no) if an interviewer from one of the HCHS/SOL field centers spoke to a participant or a participant's designated respondent and was able to confirm that the participant was alive. Participants were identified as having responded (yes/no) if either they or their designated respondents completed the AFU. Participants were identified as having fully participated (yes/no) if they (not a designated respondent) completed the interview themselves. Persistent participants ($n = 10,706$) were defined as those who participated in all 5 AFUs. Participants defined as "not persistent" were those who were eligible for all 5 AFUs but did not complete at least 1 of those AFUs ($n = 5,224$).

Motivation and satisfaction. Participants were asked to report their main reasons for participating in the study (e.g., to help the community) and how motivated they were to continue participating in the study on a scale of 1 (not motivated) to 3 (very motivated). We created an indicator variable (0/1) to identify those who were very motivated. Participants were then asked to identify any difficulties that they had in participating in the study (e.g., family obligations). We created an indicator variable (0/1) to identify those who had any 1 of 6 possible difficulties. Finally, participants were asked to report on their satisfaction, on a scale ranging from 1 (not satisfied) to 3 (very satisfied), with 8 aspects of the study (e.g., staff professionalism). We calculated participants' overall satisfaction as the sum of scores for these 8 items, ranging from 3 to 24. We identified participants as very satisfied if their overall satisfaction score was greater than 20.

Socioeconomic characteristics. We identified each participant's sex, age, and type of Hispanic/Latino background. We also defined participants' nativity and years of residence

in the United States at the time of visit 1, using 4 categories—1) born in the United States or in a US territory, 2) foreign-born with less than 10 years in the United States, 3) foreign-born with 10–20 years in the United States, and 4) foreign-born with over 20 years in the United States. Additionally, we created categorical variables to measure several socioeconomic characteristics, including education, number of hours usually worked per week, annual family income, marital status, and number of children. To retain observations with missing data on income, employment, and number of children, we included a category for missing data in each variable.

Health. At visit 1, we measured self-reported health, mental health functioning (MHF), and physical health functioning (PHF) using the 12-Item Short Form Health Survey, version 2, a well-validated instrument for both English and Spanish speakers (9–11). In the 12-Item Short Form Health Survey, self-reported health relies on a single question: “In general, would you say your health is excellent, very good, good, fair, or poor?”. MHF and PHF scores are computed and normalized with a standard algorithm, such that they are representative of the general US population with a mean of 10, a standard deviation of 10, and a range of 0–100 (9). In logistic regression models, we rescaled the MHF and PHF scores to have a mean of 0 and a standard deviation of 1. Because of high correlations between self-reported health and both MHF ($r = 0.55$) and PHF ($r = 0.29$), self-reported health was not included in logistic regression analyses.

Interview characteristics. We recorded 1) whether the interview was conducted in English or Spanish, 2) whether more than 1 venipuncture attempt was needed for the participant’s blood draw, 3) whether the participant agreed to participate in any ancillary study conducted between visit 1 and visit 2, and 4) the field center location.

Analytical plan

Statistical analysis was completed in 3 parts. First, we summarized data on selected baseline demographic, health, and interview characteristics of respondents to visit 1, persistent participants across AFU1–AFU5, and respondents to the PFQ utilized at visit 2. We evaluated mean differences in the characteristics of these samples with a 2-sided z test for age, mental health, and physical health functioning and a 2-sided t test for other variables. Second, we summarized contact, response, and participation rates over AFUs by field center. Using data from the visit 2 PFQ, we also summarized motivations to participate, challenges hindering participation, and satisfaction with participation at visit 2 by field center. We evaluated mean differences in these rates across sites using Wald’s F test for multiple comparisons with a Bonferroni correction. Third, we utilized logistic regression analyses to fit models for 3 outcomes—persistent participation in AFUs 1–5, being very motivated to participate at visit 2, and being very satisfied with participation at visit 2. Each outcome was modeled as a function of visit 1 demographic, health, and interview characteristics. Finally, we estimated the associations of moving (measured by a change in zip code between visit 1 and AFU1–AFU5) and

the average number of phone calls between AFU1 and AFU5 with persistence (see the Web Appendix, available at <https://academic.oup.com/aje>). All analyses used sampling weights and adjusted for the sample design.

To complement our statistical analysis, we describe the retention strategies utilized in HCHS/SOL. This description triangulates between information on retention strategies described in the retention manual, information on these strategies discussed in monthly retention team meetings between March 2008 and December 2016, and feedback reports from retention staff members. They help to provide a context for understanding and interpreting the statistical data on retention, motivation, and satisfaction with HCHS/SOL.

RESULTS

Retention strategies

A focus on retention began at the time of initial recruitment and during the first field center visit. The study staff at each field center created an inclusive atmosphere that emphasized building relationships and trust with participants (8). Field centers designed their clinics with family-friendly waiting rooms displaying the work of local artists, offering light snacks and beverages, and providing activities (e.g., television, magazines) for adults to engage in as they waited to begin their clinic visits. This inclusive atmosphere at the time of the first examination initiated a positive personal connection that the retention staff were able to build upon during the AFUs.

At the completion of visit 1, HCHS/SOL participants received a \$70–\$75 incentive. In AFU1, participants received a \$20 incentive to compensate for an extended interview that included a food frequency questionnaire. No financial incentive was routinely provided in AFU2–AFU5. Instead, the HCHS/SOL protocol focused on nonfinancial incentives such as the opportunity for participants to learn about their health, get free medical tests and referrals, and help researchers understand the health needs of the Hispanic/Latino community.

HCHS/SOL utilized culturally sensitive retention strategies implemented by bilingual/bicultural staff who were members of the communities in which the study was conducted. All forms of communication with participants were standardized and approved by the retention committee, a committee with representation from each field center, and the study coordinating center. To ensure that study materials were culturally and linguistically appropriate, they were developed in both English and Spanish by a translation team containing members with the diverse Hispanic/Latino backgrounds represented by HCHS/SOL participants. These materials included annual letters of invitation to participate in the next AFU, reminder letters regarding the time of the scheduled AFU call, biannual newsletters summarizing the progress of the study and health-related topics, and specialized birthday and holiday greeting cards tailored to participants’ cultural and religious backgrounds. This combination of materials helped to ensure that contact with participants was made at least once every other month.

Additionally, the HCHS/SOL retention committee coordinated activities with the HCHS/SOL community relations committee, a committee established to promote communication, understanding, and trust between field centers and the communities selected to participate in HCHS/SOL. The field center staff assisting with community relations met at least quarterly with representatives from businesses, churches, and nonprofit organizations in their communities. In collaboration with these community members, they designed an informed-consent digital versatile disk (DVD), public service announcements about the study, fact sheets for sharing the study results, and health education seminars. They also listened to community members' concerns about study participation and ideas for facilitating study participation. They then shared important insights with the HCHS/SOL retention committee.

To maximize retention, staff at each study center were encouraged to be kind, responsive, persistent, and flexible. They made personal connections with respondents and emphasized how valuable each participant's engagement in the study was in helping to understand cardiovascular health in Hispanic/Latino communities. They updated contact information at every opportunity, taking advantage of ancillary studies that built upon the HCHS/SOL cohort. During the AFU period, they called participants an average of 5.7 times on different days of the week and at different times during the day to make contact. Moreover, if phone contacts were not successful, they visited participants in the community or invited them to the clinic to allow for an in-person AFU. While relatively few participants opted for an in-person AFU, this option was essential to retain harder-to-reach participants. Contact with harder-to-reach participants was also facilitated by the availability of address and phone information for at least 2 alternate contacts designated by the primary respondent, the provision of change-of-address cards to every respondent, and the use of online search engines to obtain updated contact information. See [Table 1](#) for additional details on retention strategies.

Characteristics of HCHS/SOL participants

With an average age of 41 years, the majority of HCHS/SOL participants were female (52%), foreign-born (69%), and single (51%) and had at least 1 child (74%) ([Table 2](#)). They included a diversity of Hispanic/Latino backgrounds, with the plurality identifying as Mexican (37%). Although most worked (51%) and had at least a high school diploma or General Educational Development (GED) diploma (68%), 61% had family incomes below \$25,000/year. HCHS/SOL participants reported mostly good-to-excellent health (74%). The majority chose to complete their baseline interview in Spanish (75%), and few (9%) required multiple venipuncture attempts to complete the blood draws required as part of the clinic visit. Thirty-nine percent of participants agreed to participate in at least 1 HCHS/SOL ancillary study. Additionally, 42% of participants moved between visit 1 and AFU5 (see [Web Appendix](#)).

The baseline characteristics of participants who completed all 5 AFU interviews differed significantly from those in the full sample at visit 1 ([Table 2](#)). In comparison with

the full sample at visit 1, persistent participants were older, more often female, completed the interview in Spanish, had graduated from high school, had participated in an ancillary study, and lived in San Diego; fewer were Puerto Rican, US-born, and not married/cohabitating (i.e., single). These differences were also reflected in mean differences in the baseline characteristics of persistent versus nonpersistent participants ([Web Appendix](#)). Though there were some significant differences, the baseline characteristics of the subsample of respondents who completed the PFQ at visit 2 were similar to those of the full sample ([Table 2](#)).

AFU contact, response, and participation rates

Although staff at each field center were able to contact at least 86% of those eligible each year, AFU contact, response, and participation rates declined slowly over time ([Table 3](#)). Overall, 96% of those eligible responded and 88% of those eligible participated in AFU1. By AFU5, the response and participation rates had declined to 89% and 81%, respectively. Defined as "persistent participants," approximately 67% ($n = 10,706$) of the sample completed all 5 AFUs, varying from 55% in the Bronx to 76% in Miami. Among those who missed at least 1 of the 5 AFUs (33%; $n = 5,224$), 40% missed exactly 1 AFU.

Motivations and satisfaction

Overall, 82% of those who completed the PFQ at visit 2 were persistent participants who had completed visit 1 5.8 years (i.e., 79.7 months) previously ([Table 4](#)). The majority (62%) reported being very motivated to continue their participation in the study. The primary and secondary motivations for participation in HCHS/SOL were "to learn about my health" (89%) and "to help the community" (87%). Participants also valued opportunities to get free medical tests and referrals (71%) and to participate in additional studies (72%). Only 41% of participants reported monetary incentives as a primary reason for participation. Participants in Chicago and San Diego were the most motivated by monetary incentives.

Thirty-eight percent of participants faced 1 or more challenges to participation. These included work obligations (20%), family obligations (15%), residential instability (15%), lack of time (7%), and transportation difficulties (2%). Few cited difficulties or discomfort during the clinic visit as a problem (1%).

Aspects of the study which helped to promote participant satisfaction and potentially encouraged their commitment to the study included being very satisfied with the professionalism of the staff (80%), having the option to complete the interview in either English or Spanish (65%), the receipt of AFU reminder letters (72%), and the flexibility of AFU call times (58%). Participants were also very satisfied with the receipt of retention materials—including health information about themselves (63%), health education materials (74%), the study newsletter (64%), and birthday or holiday cards (70%). On average, participants reported a score of 21 on the overall satisfaction index. Sixty-two percent of participants were very satisfied (i.e., had a score over 20).

Table 1. Retention Strategies Used in the Hispanic Community Health Study/Study of Latinos, 2008–2011^a

Type of Strategy	Purpose	Details
Community involvement	Learn from community members and ensure that the study design is appropriate for the community's background and experience; develop community support for the study; promote education and awareness of research	Create community relations committees at each site consisting of community members and project staff Consult regularly with community members regarding protocol and participation Develop public service announcements about the purpose and value of the study
Study personnel	Promote professionalism, teamwork, and continuity of staff	Share results from the study through fact sheets and community forums Hire bilingual/bicultural staff from within the participating communities Encourage personnel to be kind, responsive, and flexible Conduct training for interviews
Recruitment	Build rapport and trust with participants during initial contact	Prepare a culturally and linguistically tailored informed-consent DVD Inform participants that they will be followed over time Spend time answering participants' questions about the study Establish community- and family-centered clinic facilities
Financial incentives	Provide a meaningful incentive commensurate with the time required for participation	Provide financial incentives at initial recruitment with lower incentives for shorter annual follow-up Allow participants to obtain additional financial incentives through participation in ancillary studies
Nonfinancial incentives	Show appreciation for participants' engagement with the study and appeal to altruism and norms of cooperation	Emphasize the value of helping to improve the health of Hispanic/Latino populations Provide inexpensive tokens of appreciation with the study logo (e.g., magnets, wall calendars)
Reimbursement	Minimize the costs of participation for participants	Provide seasonal incentives (e.g., frozen turkeys for Thanksgiving) Reimburse participants for local travel costs (taxicabs, bus fare, mileage) Reimburse participants for child-care costs
Direct benefits	Provide benefits to participants in the study	Provide information on health test results (e.g., cholesterol screening) Provide referrals to health-care providers

Table continues

Table 1. Continued

Type of Strategy	Purpose	Details
Contact and scheduling	Develop a systematic process for appointment scheduling and monitoring of retention	Obtain the names of multiple contacts for each participant, including 2 contacts not residing with participants Obtain multiple forms of contact information for each participant (i.e., home phone, cell phone, address, e-mail)
Follow-up visit characteristics	Minimize participant burden	Create a retention committee to meet regularly to discuss retention strategies and challenges with retention across research sites/communities Offer flexible clinic hours (e.g., mornings, evenings, weekends) Offer multiple modes for follow-up interviews (e.g., telephone, in-clinic, in-home)
Communications	Maintain regular contact with participants, keep them informed about the study, and help them remember the annual follow-up schedule	Coordinate follow-up visits with ancillary studies Create an identifiable study logo reflecting community values Develop a study website and a Facebook page (Facebook, Inc., Menlo Park, California) for participants (not researchers) to access information about the study Send participants holiday and birthday cards tailored to their religious or cultural preferences Send participants biannual newsletters regarding the study Mail reminder postcards or letters at least 1 week before appointments Remind participants of follow-up appointments during clinic visits Send thank-you notes after follow-up calls and visits Subscribe to and use online search engines to obtain updated contact information for respondents
Special tracking methods	Improve retention of hard-to-reach participants	Conduct street-level outreach for participants who cannot be contacted via phone

Abbreviation: DVD, digital versatile disk.

^a Themes and descriptions are adapted from Robinson et al. (5). Details in the strategies are specific to the Hispanic Community Health Study/Study of Latinos.

Table 2. Baseline Characteristics of Respondents at Visit 1 (2008–2011), Persons Who Persistently Participated in All 5 Annual Follow-up Interviews (2009–2016), and Persons Who Responded to the Participant Feedback Questionnaire at Visit 2 (2014–2015), Hispanic Community Health Study/Study of Latinos

Characteristic	Full Sample (Visit 1) (n = 16,243)			Persistent Participants (n = 10,706)			PFQ Subsample (Visit 2) (n = 5,227)		
	Mean	%	95% CI	Mean	%	95% CI	Mean	%	95% CI
Demographic characteristics									
Female sex		52.2	51.1, 53.2		55.5	54.2, 56.7		53.8	51.9, 55.7
Age, years	41.0		40.5, 41.5	43.4		42.8, 43.9	43.0		42.2, 43.8
Hispanic/Latino heritage									
Dominican		9.9	8.6, 11.4		8.9	7.6, 10.3		8.4	6.9, 10.1
Central American		7.4	6.4, 8.5		7.8	6.6, 9.2		8.5	7.0, 10.3
Cuban		19.9	16.8, 23.4		23.2	19.9, 27.0		21.6	18.2, 25.5
Mexican		37.3	34.2, 40.6		37.8	34.4, 41.4		37.1	33.3, 41.0
Puerto Rican		16.2	14.7, 17.8		13.1	11.7, 14.7		15.1	13.3, 17.1
South American		5.0	4.4, 5.7		5.5	4.8, 6.3		5.0	4.1, 6.2
Other/mixed/missing data		4.2	3.7, 4.8		3.6	3.0, 4.2		4.3	3.4, 5.5
Nativity and duration of residence in US									
Born in US/US territory		31.1	29.1, 33.1		25.5	23.5, 27.5		28.7	26.1, 31.4
Foreign-born with <10 years in US		26.8	25.0, 28.8		28.8	26.6, 31.0		28.5	25.8, 31.3
Foreign-born with 10–20 years in US		24.1	23.0, 25.3		25.4	24.0, 26.8		23.5	21.6, 25.6
Foreign-born with >20 years in US		18.0	17.0, 19.0		20.4	19.2, 21.6		19.3	17.7, 21.1
High school graduation/GED diploma or more		67.7	66.3, 69.1		69.4	67.7, 70.9		67.9	65.6, 70.1
Employment status									
Not employed		48.5	47.1, 49.9		48.8	47.3, 50.3		49.5	47.2, 51.8
Employed for <36 hours/week		18.2	17.3, 19.1		18.0	17.0, 18.9		17.7	16.2, 19.3
Employed for 36–45 hours/week		20.0	19.1, 21.0		21.2	20.1, 22.3		19.1	17.5, 20.9
Employed for >45 hours/week		11.4	10.7, 12.3		11.0	10.2, 11.9		12.4	11.0, 14.1
Income ≥\$25,000/year		39.3	37.3, 41.4		40.8	38.4, 43.2		37.9	35.4, 40.5
Married/cohabitating		48.8	47.3, 50.4		52.8	50.9, 54.6		48.6	46.0, 51.2
No children		25.7	24.5, 26.9		22.6	21.2, 24.0		24.7	22.6, 26.9
Health characteristics									
Good–excellent self-reported health		74.2	72.8, 75.4		74.4	72.9, 75.9		72.4	70.4, 74.3
Mental health functioning score	49.1		48.8, 49.4	49.5		49.2, 49.8	49.3		48.8, 49.8
Physical health functioning score	50.0		49.7, 50.2	49.9		49.6, 50.2	49.2		48.7, 49.7

Table continues

Table 2. Continued

Characteristic	Full Sample (Visit 1) (n = 16,243)			Persistent Participants (n = 10,706)			PFQ Subsample (Visit 2) (n = 5,227)		
	Mean	%	95% CI	Mean	%	95% CI	Mean	%	95% CI
Interview characteristics									
Interview conducted in Spanish		74.7	72.9, 76.5		79.2	77.4, 81.0		77.3	74.7, 79.6
> 1 Venipuncture attempt		9.1	8.4, 9.8		9.0	8.2, 9.8		10.5	9.2, 12.0
Participation in any ancillary study		38.7	36.9, 40.5		46.7	44.6, 48.9		35.0	31.9, 38.2
Field center									
Bronx, New York		28.9	26.1, 32.0		26.9	23.3, 30.9		24.4	21.3, 27.7
Chicago, Illinois		15.8	14.0, 17.9		16.0	13.9, 18.2		16.5	14.2, 19.2
Miami, Florida		29.2	25.2, 33.6		22.8	20.2, 25.6		32.6	28.1, 37.5
San Diego, California		26.0	22.8, 29.6		34.3	29.9, 39.0		26.5	22.8, 30.5

Abbreviations: CI, confidence interval; GED, General Educational Development; PFQ, Participant Feedback Questionnaire; US, United States.

^a The table shows unweighted numbers and weighted estimates adjusted for study design. A total of 16,243 participants at visit 1 were eligible for an annual follow-up interview. Of these, 10,706 were classified as persistent participants. At visit 2, a total of 5,227 participants completed a PFQ. Percentages of the full sample who were missing data on income (9%), employment (2%), number of children (2%), and mental/physical health (1%) are not shown because of space limits.

Associations with persistence, motivation, and satisfaction

Persistent participation was associated with being older, female, foreign-born, and married/cohabitating (Table 5). Persons who had a high school diploma or GED, were employed for 36–45 hours/week, and had an income of at least \$25,000/year were also among those most likely to participate across multiple AFUs. Finally, good MHF and participation in an ancillary study were associated with a higher likelihood of persistent participation. We found no associations between participation and Hispanic/Latino background, language of interview, PHF, or multiple venipuncture attempts. After adjustment for each of these demographic, health, and interview characteristics, participants in Miami were the most likely to persist in the study and participants from the Bronx were the least likely.

We identified few significant associations between high motivation or high satisfaction and our demographic, health, and interview characteristics. Older participants and females were significantly more likely to report both high motivation and high satisfaction than younger persons and males. Participants completing their interviews in Spanish reported higher motivation than those with English interviews. Additionally, foreign-born individuals with 10–20 years of residence in the United States were more likely to report high satisfaction than the US-born. After adjustment for demographic, health, and interview characteristics, participants from Chicago reported the lowest levels of motivation and satisfaction.

DISCUSSION

To our knowledge, the landmark HCHS/SOL is the largest and longest study of Hispanics/Latinos in the history of the United States. The sample represents the 5 largest Hispanic/Latino heritage groups (Mexican, Puerto Rican, Dominican, South American, and Central American) living in the United States today and includes immigrants of first, second, and third-plus generations. Moreover, it provides comprehensive epidemiologic data with repeated genetic, biological, and psychosocial measures.

The HCHS/SOL has maintained high response and participation rates across the first 5 years of AFU interviews (Figure 1). In each of the first 5 years of AFU, the HCHS/SOL maintained response rates of 88.6%–95.5%, and 81.1%–87.9% of participants completed the interview themselves. These response rates compare favorably to response rates from previous longitudinal cohort studies with Hispanic/Latino participants. The National Longitudinal Study of Adolescent to Adult Health, a cohort study of youth aged 12–18 years in 1994–1995, achieved response rates of 80% among all participants and 75% among Hispanic/Latino participants over a 13-year period (12). Focusing on an older population (ages ≥ 51 years), the Health and Retirement Study, which began in 1992, had response rates of 78% among nonminority participants and 77% among Hispanics/Latinos in 2008 (13).

Given the prevalence of anti-immigrant sentiment in the United States (14), a predominant concern among those

Table 3. Participant Response Rates by Field Center and Annual Follow-up Interview, Hispanic Community Health Study/Study of Latinos, 2009–2016^a

Field Center and Response Status	Follow-up Interview																		
	AFU1			AFU2			AFU3			AFU4			AFU5			Overall (AFUs 1–5)			
	No. of Persons	%		No. of Persons	%		No. of Persons	%		No. of Persons	%		No. of Persons	%		No. of Persons	%		
Bronx, New York	4,049			4,025			4,004			3,987			3,960			3,960			3,960
Contacted		95.9 ^b			92.3 ^{b,c,d}			90.8 ^{b,c,d}											85.7 ^{b,d}
Responded		94.9 ^b			91.7 ^{b,c,d}			90.3 ^{b,d}											84.8 ^{b,c,d}
Participated		83.2 ^{b,c,d}			81.2 ^{b,c,d}			78.7 ^{c,d}											73.8 ^{b,c,d}
Chicago, Illinois	4,093			4,080			4,068			4,059			4,051			4,051			54.6 ^{b,c,d}
Contacted		96.0			96.1 ^e			94.5 ^e											82.6 ^{b,d,e}
Responded		94.6			95.5 ^e			93.5											79.2 ^{b,d,e}
Participated		87.3 ^{d,e}			89.0 ^{d,e}			87.5 ^e											66.8 ^{d,e}
Miami, Florida	4,020			4,003			3,980			3,965			3,838			3,938			
Contacted		96.4			95.0 ^e			93.1 ^e											86.2 ^{c,e}
Responded		95.5			94.2 ^e			92.3 ^e											84.4 ^{c,e}
Participated		92.7 ^{b,c,e}			90.9 ^{b,c,e}			86.1 ^{b,e}											76.2 ^{b,c,e}
San Diego, California	4,035			4,027			4,015			3,998			3,981			3,981			
Contacted		97.8 ^e			96.6 ^e			95.3 ^e											88.8 ^{c,e}
Responded		97.0 ^e			96.0 ^e			94.9 ^e											87.7 ^{c,e}
Participated		88.3 ^{d,e}			87.7 ^{d,e}			85.1 ^d											71.3 ^{d,e}
Overall	16,197			16,135			16,067			16,009			15,930			15,930			
Contacted		96.5			95.0			93.4											83.3
Responded		95.5			94.3			92.7											81.3
Participated		87.9			87.2			84.4											67.2

Abbreviation: AFU, annual follow-up.

^a The “No.” columns show the number of persons eligible for participation at the time of each AFU who had no missing data on the characteristics shown in Table 2. Eligible participants at each AFU were those who completed the visit 1 examination, were alive, and had not refused to be contacted for future studies. Percentages were calculated by dividing the number of persons contacted, responding, or participating by the number eligible at each AFU.

^b Significantly different from San Diego at $P < 0.05$.

^c Significantly different from Chicago at $P < 0.05$.

^d Significantly different from Miami at $P < 0.05$.

^e Significantly different from the Bronx at $P < 0.05$.

Table 4. Motivations, Challenges, and Satisfaction Levels Reported by Participants at Study Visit 2, by Field Center, Hispanic Community Health Study/Study of Latinos, 2014–2015^a

Characteristic	Field Center														
	Bronx, New York (n = 1,051)			Chicago, Illinois (n = 1,372)			Miami, Florida (n = 1,385)			San Diego, California (n = 1,419)			All Centers (n = 5,227)		
	Mean	%	95% CI	Mean	%	95% CI	Mean	%	95% CI	Mean	%	95% CI	Mean	%	95% CI
Persistent participation (AFUs 1–5)	74.6 ^b		70.3, 78.4	78.2 ^b		74.6, 81.3	89.7 ^{c,d,e}		87.0, 91.9	80.8 ^b		76.3, 84.7	81.8		79.8, 83.6
Time between visits 1 and 2, months	68.9 ^{b,d,e}		68.3, 69.5	72.4 ^{b,c}		71.8, 73.0	67.0 ^{c,d,e}		66.4, 67.6	72.0 ^{b,c}		71.2, 72.7	69.7		69.2, 70.1
Average no. of call attempts made during AFUs 1–5	4.7 ^{b,e}		4.5, 5.0	5.1 ^{b,e}		4.9, 5.3	3.3 ^{c,d,e}		3.1, 3.5	5.8 ^{b,c,d}		5.4, 6.3	4.6		4.4, 4.8
Motivation for participation															
To help my community	87.3 ^{b,d,e}		83.7, 90.2	96.7 ^{b,c}		94.9, 97.9	74.3 ^{c,d,e}		70.8, 77.6	97.2 ^{b,c}		95.7, 98.2	87.3		85.4, 89.0
To learn more about my health	92.0 ^{b,d}		89.8, 93.8	97.1 ^{b,c}		95.6, 98.1	78.0 ^{c,d,e}		74.7, 81.0	94.3 ^b		92.5, 95.7	88.9		87.4, 90.2
To participate in additional studies	78.8 ^{b,d,e}		74.9, 82.3	94.0 ^{b,c,e}		92.1, 95.4	45.6 ^{c,d,e}		41.9, 49.3	86.0 ^{b,c,d}		82.5, 88.8	72.4		69.8, 74.8
To get free medical tests and referrals	66.9 ^{d,e}		61.8, 71.6	90.3 ^{b,c,e}		87.1, 92.8	59.5 ^{d,e}		56.2, 62.7	75.4 ^{b,c,d}		71.3, 79.1	70.6		68.5, 72.7
To get the monetary incentive	38.0 ^{d,e}		33.7, 42.4	48.8 ^{b,c}		44.8, 52.9	33.3 ^{d,e}		29.2, 37.5	49.1 ^{b,c}		44.1, 54.0	41.2		38.9, 43.5
Very motivated to participate	57.4 ^b		53.3, 61.3	52.1 ^b		48.1, 56.2	72.6 ^{c,d,e}		68.8, 76.0	59.3 ^b		55.6, 62.8	62.0		59.8, 64.1
Any challenges for participation	50.0 ^{b,e}		45.7, 54.2	50.7 ^{b,e}		46.9, 54.5	22.8 ^{c,d,e}		19.7, 26.3	38.9 ^{b,c,d}		35.0, 43.0	38.3		36.1, 40.6
Specific challenges for participation															
Family obligations	25.1 ^{b,e}		21.5, 29.1	20.0 ^b		17.0, 23.3	4.1 ^{c,d,e}		3.1, 5.6	14.0 ^{b,c}		11.0, 17.7	14.5		12.9, 16.3
Work obligations	23.9 ^e		20.1, 28.1	28.5 ^{b,e}		25.5, 31.8	12.2 ^{c,d,e}		9.6, 15.3	20.4 ^{b,d}		16.8, 24.6	19.9		18.1, 21.9
Time commitment	15.9 ^{b,d,e}		12.9, 19.5	4.5 ^{b,c}		3.2, 6.3	1.6 ^{c,d,e}		0.9, 2.7	8.6 ^{b,c}		6.0, 12.2	7.4		6.3, 8.8
Residential instability	17.8		14.1, 22.2	24.6 ^{b,e}		21.1, 28.4	11.8 ^d		9.2, 15.0	11.8 ^d		8.6, 16.0	15.4		13.6, 17.3
Transportation difficulties	4.1 ^{b,d}		2.6, 6.4	0.2 ^{c,e}		0.1, 0.9	0.6 ^{c,e}		0.3, 1.1	2.0 ^{b,d}		1.1, 3.6	1.7		1.2, 2.4
Discomfort with clinic visits/tests	2.0		1.0, 3.8	0.9		0.4, 2.2	0.7		0.4, 1.3	1.0		0.5, 2.1	1.2		0.8, 1.7

Table continues

Table 4. Continued

Characteristic	Field Center														
	Bronx, New York (n = 1,051)			Chicago, Illinois (n = 1,372)			Miami, Florida (n = 1,385)			San Diego, California (n = 1,419)			All Centers (n = 5,227)		
	Mean	%	95% CI	Mean	%	95% CI	Mean	%	95% CI	Mean	%	95% CI	Mean	%	95% CI
Satisfaction items															
English/Spanish interview option	55.4 ^{b,e}	50.9	59.8	50.6 ^{b,e}	47.0	54.2	78.1 ^{c,d,e}	74.7	81.1	67.0 ^{b,c,d}	62.5	71.3	65.1	62.8	67.3
Staff respect and professionalism	76.0 ^{b,d,e}	72.2	79.4	68.4 ^{b,c,e}	65.3	71.4	85.3 ^{c,d}	81.9	88.1	84.7 ^{c,d}	81.8	87.3	80.1	78.4	81.7
Flexibility of AFU call times	45.9 ^{b,e}	41.4	50.5	44.5 ^{b,e}	40.7	48.2	71.6 ^{c,d,e}	67.7	75.2	59.2 ^{b,c,d}	54.9	63.4	57.6	55.2	59.9
AFU reminder letters	60.4 ^{b,e}	55.6	64.9	64.4 ^{b,e}	60.8	67.8	84.5 ^{c,d,e}	81.2	87.3	73.2 ^{b,c,d}	69.6	76.6	72.3	70.1	74.4
Receipt of personal health information	56.9 ^b	52.5	61.2	51.4 ^{b,e}	47.4	55.3	73.1 ^{c,d,e}	69.4	76.5	64.1 ^{b,d}	60.6	67.5	63.2	61.0	65.3
Receipt of health education information	68.3 ^b	63.6	72.7	63.6 ^{b,e}	60.2	67.0	85.8 ^{c,d,e}	82.7	88.5	72.5 ^{b,d}	68.9	75.9	74.4	72.3	76.3
Receipt of study newsletter	55.0 ^b	49.7	60.1	52.4 ^b	48.4	56.3	83.8 ^{c,d,e}	80.4	86.7	56.1 ^b	51.9	60.2	64.3	61.7	66.8
Receipt of birthday/holiday cards	61.3 ^b	56.3	66.1	65.8 ^b	62.4	69.0	79.2 ^{c,d,e}	75.2	82.7	69.4 ^b	65.6	73.0	70.0	67.8	72.2
Overall satisfaction index ^f															
Satisfaction index score	20.3 ^{b,e}	19.9	20.6	20.3 ^{b,e}	20.1	20.5	22.1 ^{c,d,e}	21.8	22.3	21.2 ^{b,c,d}	21.0	21.4	21.1	20.9	21.3
Very satisfied (score >20)	51.5 ^{b,e}	46.5	56.5	48.3 ^{b,e}	44.7	51.9	74.6 ^{c,d,e}	70.6	78.2	64.7 ^{b,c,d}	60.7	68.6	62.0	59.6	64.4

Abbreviations: AFU, annual follow-up; CI, confidence interval.

^a The table shows unweighted numbers and weighted estimates adjusted for study design. The n's represent the numbers of participants at study visit 2 who completed the Participant Feedback Questionnaire and had no missing data on the characteristics shown in Table 2.

^b Significantly different from Miami at $P < 0.05$.

^c Significantly different from the Bronx at $P < 0.05$.

^d Significantly different from Chicago at $P < 0.05$.

^e Significantly different from San Diego at $P < 0.05$.

^f Participants were asked to report their level of satisfaction, on a scale from 1 (not satisfied) to 3 (very satisfied), with 8 aspects of the study (e.g., staff professionalism). Participants' overall satisfaction was calculated as the sum of scores for these 8 items, ranging from 3 to 24. Participants were defined as "very satisfied" if their overall satisfaction score was greater than 20.

Table 5. Odds Ratios (Logistic Regression Analyses) for Persistent Participation in All 5 Annual Follow-up Interviews (2009–2016), Being Very Motivated to Participate at Study Visit 2 (2014–2015), and Being Very Satisfied With Participation at Visit 2 (2014–2015), Hispanic Community Health Study/Study of Latinos^a

Characteristic	Persistent Participation (n = 15,930)		Being Very Motivated (n = 5,227)		Being Very Satisfied (n = 5,227)	
	OR	95% CI	OR	95% CI	OR	95% CI
Demographic characteristics						
Female sex (vs. male)	1.47	1.34, 1.62	1.23	1.00, 1.51	1.44	1.19, 1.75
Age, years	1.03	1.03, 1.04	1.01	1.00, 1.02	1.01	1.00, 1.02
Hispanic/Latino heritage (vs. Mexican)						
Dominican	1.01	0.78, 1.30	1.20	0.72, 2.01	1.17	0.72, 1.89
Central American	0.90	0.70, 1.17	1.46	0.93, 2.29	1.72	1.10, 2.68
Cuban	0.80	0.60, 1.07	1.48	0.87, 2.52	1.32	0.82, 2.12
Puerto Rican	0.96	0.74, 1.25	1.74	1.09, 2.78	2.00	1.24, 3.23
South American	0.93	0.71, 1.20	1.02	0.62, 1.68	0.89	0.58, 1.35
Other	0.94	0.69, 1.30	1.71	0.95, 3.08	1.53	0.81, 2.88
Nativity and duration of residence in US (vs. US-born)						
Foreign-born with <10 years in US	1.40	1.12, 1.75	1.37	0.96, 1.94	1.17	0.79, 1.72
Foreign-born with 10–20 years in US	1.32	1.07, 1.63	1.32	0.96, 1.83	1.56	1.07, 2.29
Foreign-born with >20 years in US	1.25	1.01, 1.54	1.22	0.86, 1.72	1.41	0.99, 2.01
High school graduation/GED diploma or more (vs. less than high school)	1.24	1.11, 1.39	1.07	0.89, 1.28	1.08	0.89, 1.32
Employment status (vs. not employed)						
Employed for <36 hours/week	0.98	0.85, 1.14	1.01	0.79, 1.29	0.89	0.69, 1.14
Employed for 36–45 hours/week	1.16	1.00, 1.34	1.06	0.82, 1.36	0.97	0.76, 1.23
Employed for >45 hours/week	0.97	0.81, 1.17	1.03	0.75, 1.42	0.87	0.63, 1.19
Income ≥\$25,000/year (vs. <\$25,000/year)	1.29	1.14, 1.45	1.04	0.86, 1.24	0.98	0.79, 1.20
Married/cohabitating (vs. single)	1.17	1.05, 1.32	1.11	0.92, 1.33	1.18	0.98, 1.43
No children (vs. any children)	1.21	1.03, 1.42	0.99	0.74, 1.32	0.94	0.72, 1.23
Health characteristics						
Mental health functioning score	1.10	1.04, 1.17	0.94	0.85, 1.05	0.97	0.88, 1.07
Physical health functioning score	0.99	0.94, 1.05	0.98	0.88, 1.08	1.02	0.93, 1.13
Interview characteristics						
Interview conducted in Spanish (vs. English)	1.01	0.86, 1.18	0.69	0.51, 0.92	1.08	0.79, 1.48
No. of venipuncture attempts (vs. 1 attempt)						
0	0.22	0.11, 0.44	1.69	0.50, 5.69	4.77	1.43, 15.86
>1	0.92	0.77, 1.10	1.23	0.91, 1.65	0.94	0.69, 1.27
Participation in ≥1 ancillary study (vs. 0)	2.60	2.30, 2.94	1.16	0.97, 1.40	1.12	0.92, 1.36
Field center (vs. San Diego, California)						
Bronx, New York	0.60	0.46, 0.79	0.69	0.44, 1.09	0.42	0.28, 0.65
Chicago, Illinois	1.00	0.82, 1.22	0.70	0.54, 0.91	0.46	0.35, 0.59
Miami, Florida	1.53	1.12, 2.10	1.31	0.79, 2.16	1.16	0.74, 1.83

Abbreviations: CI, confidence interval; GED, General Educational Development; OR, odds ratio; US, United States.

^a The table shows unweighted numbers and weighted estimates adjusted for study design. ORs for indicators of missing values on income, employment, number of children, and mental/physical health are not shown because of space considerations.

conducting longitudinal cohort studies with Hispanics/Latinos has been that foreign-born Hispanics/Latinos and their US-born family members might be less willing to participate in studies, especially those sponsored by government agencies. We found evidence to the contrary. Foreign-born participants were the most likely to continually participate across the first 5 years of follow-up for HCHS/SOL. Moreover, those who had lived in the United States for 10–20 years reported the highest levels of satisfaction with the study. However, by the completion of visit 2 in 2017, we had identified 1,224 participants (7.5% of the visit 1 sample) who had relocated outside of the United States or had moved more than 100 miles (160 km) from the nearest HCHS/SOL field center.

In the HCHS/SOL, the hardest-to-reach participants were young, single, US-born males without a high school diploma or GED and with incomes under \$25,000/year. Persons who were not employed and those who had poorer MHF were also among the hardest-to-reach participants. These findings are consistent with previous research on retention (3). These population groups have fewer social connections and community ties that could motivate and facilitate engagement in research. Although most participants were motivated to participate by an interest in learning about their own health or helping their communities, financial incentives may be more important for retention of these harder-to-reach populations.

Our results from participant feedback at visit 2 also underscored the importance of employing bilingual/bicultural staff who treat participants with respect and professionalism. Additionally, the use of culturally tailored retention materials to maintain regular contact with participants throughout the year and flexible interview schedules to allow participants to coordinate their participation in HCHS/SOL with their family and work obligations was valued by participants.

Limitations

The primary limitation of this study was the absence of data on participants who were lost to follow-up 1–5 years after baseline. We only had baseline information from visit 1 on these participants and were not able to evaluate their motivations or satisfaction. Additionally, this study of retention reflects only Hispanic/Latino participants living near HCHS/SOL field centers. These field centers are located in large metropolitan areas that have had a strong historical presence of Hispanic/Latino and immigrant communities. Studies of Hispanics/Latinos living in more suburban or rural areas and in areas with less of a history of a Hispanic/Latino and immigrant presence may have different retention experiences.

Overall, this study demonstrates that retention of Hispanics/Latinos in prospective/longitudinal cohort studies can be facilitated through the employment of bilingual/bicultural staff and the development of culturally tailored retention materials. However, extra efforts must be made to retain the hardest-to-reach Hispanic/Latino populations, which include young, single, US-born males without a high school diploma or GED.

Lessons Learned

- High retention rates for Hispanics/Latinos in large prospective cohort studies are possible. In each of the first 5 years of annual follow-up, the HCHS/SOL maintained response rates of 88.6%–95.5%.
- To achieve high retention rates, studies of Hispanics/Latinos should employ bilingual/bicultural staff who treat participants with respect and professionalism, use culturally tailored retention materials to maintain regular contact with participants, and provide flexible interview schedules to allow participants to coordinate study participation with their family and work obligations.
- The most difficult Hispanic/Latino populations to retain include young, single, US-born males without a high school diploma or GED. Additional efforts, including financial incentives, may be needed to retain these harder-to-reach populations.

Figure 1. Lessons learned from the Hispanic Community Health Study/Study of Latinos.

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