

# LEVELS OF PARTICIPANTS SATISFACTION WITH INITIAL CONTACT AND EXAMINATION VISIT: THE HISPANIC COMMUNITY HEALTH STUDY/STUDY OF LATINOS (HCHS/SOL)

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**Objective:** This study examined perceived satisfaction among Hispanic/Latino individuals who participated in a baseline examination for the Hispanic Community Health Study/Study of Latinos (HCHS/SOL), a large cohort study of 16,415 adults living in four selected communities.

**Method:** An estimated 22% ( $n = 3,584$ ) of participants completed a questionnaire regarding satisfaction with staff attention, the overall experience during the study examination, and the influence of the informed consent digital video disc (DVD).

**Results:** The majority of participants who completed the questionnaire expressed overall satisfaction with the study. Most participants reported that staff were friendly, courteous and respectful and study test procedures were clearly explained. Participants who preferred to complete the interview in Spanish felt that the informed consent DVD positively influenced their ability to make an informed decision to enroll in the study. Participants who preferred to complete the interview in English tended to report that the baseline examination was longer than expected compared with participants who completed the interview in Spanish.

**Conclusion:** Results demonstrate that culturally and linguistically trained staff and the use of the study's informed consent DVD were effective in explaining study procedures and positively influenced decisions to participate in the HCHS/SOL study. These results can inform recruitment and enrollment strategies for future participation of minority groups into longitudinal cohort studies. *Ethn Dis.* 2016;26(3):435-442; doi:10.18865/ed.26.3.435

**Keywords:** Recruitment; Retention; Hispanics/Latinos; Participant Satisfaction; Longitudinal Population-based Studies

## INTRODUCTION

In order to better address health disparities that disproportionately affect ethnic minorities, recruitment of these populations is needed in epidemiological research. There are multiple reported barriers to recruitment and retention of ethnic minorities in research studies,<sup>1-3</sup> particularly in longitudinal cohort studies<sup>4, 5</sup> and clinical trials.<sup>6-8</sup> Some of the barriers are related to study research design<sup>9</sup> and a lack of cultural and linguistic appropriate strategies and measures, particularly for minority participants from low socioeconomic backgrounds.<sup>10,11</sup> Among Hispanics/Latinos, these types of barriers are marked and include other significant limitations such as low inclusion of bilingual and culturally competent trained staff<sup>12</sup> who represent the same heritage background as those recruited into the research.<sup>13</sup> Research findings

have also identified barriers among participants related to the limited knowledge and/or understandings of research studies, mistrust of the research community, time constraints, and cost of travel to the study location.<sup>8, 9,14</sup> Difficult procedures and lengthy questionnaires also impede the recruitment and retention of ethnic minority groups into research.<sup>15,16</sup>

The limited number of contemporary studies conducted among Hispanics/Latinos provides marginal information to effectively design and implement research studies that include culturally appropriate methods and strategies to recruit and retain Hispanics/Latinos. Previous literature suggests staff characteristics (eg, culturally and linguistically competent), attitudes and enthusiasm for the research study, along with personalized attention can have a positive effect on recruitment and retention efforts among participants in follow-

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up cohort studies and prevention research.<sup>13,17</sup> In particular, successful retention of study participants in longitudinal studies should begin during the recruitment phase. Willingness to participate in this type of study can be assessed during the initial stages of the screening process by allowing ample time for potential participants to consider participation in the research study.<sup>18</sup> Hunt and White (1998) stressed the importance of communicating the expectations of participation and necessary tasks involved to maximize retention efforts and ensure participant satisfaction.<sup>17</sup> Inclusion of culturally and linguistically aligned, well-trained and dedicated staff throughout the recruitment, data collection and follow-up phase is pivotal to retention and study acceptability.<sup>19</sup> Particular importance should be placed on hiring staff that best represents both the heritage and local language of the study participants.<sup>20</sup> Training of staff is essential to maintain linguistic and cultural competency to effectively carry out related study activities and improve cultural appropriateness and overall participant satisfaction. Among Hispanics/Latinos, traditional cultural values such *personalismo*, *respeto*, *familismo* and gender norms are important factors to consider throughout all aspects of the study.<sup>21,22</sup>

While findings in literature have identified important components described previously that may be predictive of study participation and retention,<sup>19</sup> no research to date, to our knowledge, has focused on evaluating the relative effectiveness of these strategies for recruiting and retaining Hispanic/Latino partici-

pants. Recruiting and retaining participants is especially challenging for prospective population-based studies which, in part, is due to the length involved in longitudinal cohort studies. In order to increase involvement of minority populations in research studies it is essential to gain a better understanding of the determinants that influence participation.

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amine perceived satisfaction among Hispanic/Latino participants to guide future research practices and procedures in longitudinal cohort studies. Specifically, the primary goal of this research was to assess the perceived satisfaction and experience during the baseline visit among participants of the Hispanic Community Health Study/Study of Latinos (HCHS/SOL) using a *Participant Feedback Questionnaire* completed at the end of the baseline examination visit. The questionnaire assessed the

level of satisfaction regarding aspects of the baseline examination, which included recruitment experience, baseline examination, overall staff attention, and the field center environment. The secondary aim of our study was to examine the extent to which the viewing of the informed consent DVD for the study influenced decisions among individuals to participate in the study. Lastly, we assessed the perceived burden of the 7.5-hour baseline examination among participants in the HCHS/SOL study.

## METHODS

Participants in HCHS/SOL included 16,415 adults aged 18 to 74 years living in Bronx, NY; Chicago, IL; Miami, FL; and San Diego, CA at time of recruitment. Eligibility, study examination methods, design and sampling are described in more detail in previous publications.<sup>23, 24</sup> This study was approved by the institutional review boards at the data coordinating center and at each field center where all participants gave written consent.

Following completion of the baseline examination, a self-administered, optional participant feedback questionnaire was provided to participants in the participants' preferred language. The questionnaire was developed by the HCHS/SOL Retention Committee, with national membership representation of field center investigators, research staff and sponsors. The purpose of the questionnaire was to: 1) improve study operations; 2) assess perceived satisfaction of the study visit; and 3) determine factors that

facilitate the retention of Hispanics/Latinos in longitudinal studies. The questionnaire consisted of 16 closed-ended questions targeting aspects of the recruitment process, the baseline examination visit, the overall staff attention, and the field center environment. The estimated average time to complete the questionnaire was about 2 minutes. Only a select number of questions were analyzed. Three open ended questions asked: 1) how the examination visit could be more comfortable; 2) how the overall study experience could be improved; and 3) if respondent wanted to make additional comments. We examined the frequencies of the questions and summarized the open-ended questions.

Approximately 22% of the total HCHS/SOL participants completed the participant feedback questionnaire. There were several reasons for the relatively low participation: 1) delay in the implementation of the feedback questionnaire; 2) the questionnaire was optional due to the length (7.5 hours) of the complete examination visit and desire to minimize burden; and, 3) other logistics such as participant's flow at the end of the baseline examination visit. When time permitted, participants were asked to complete the feedback questionnaire at the end of the visit, or to return the form with other study-related assessments.

An informational DVD was developed by the HCHS/SOL team of investigators through a contract with a professional media consultant. The informed consent DVD was shown to individuals who agreed to participate in the study upon arrival to the local field center for the study exami-

nation visit as part of the informed consent process. This DVD included 15-20 minutes of background information illustrating the historical significance of the study, and depicting key players as spokespersons (ie, study participants, principal investigators, representatives of the funding sponsors, and key members of the research staff). The DVD also described the four study field centers and the locations where the study examinations were to take place, description of the study procedures, and the time commitment and importance of long-term participation to the success of the study. Trained bilingual and bicultural research staff, including those involved in the initial screening for eligibility and enrollment, were trained to respond to participants' questions.

### Statistics

To analyze the closed-ended questions and demographic information, SAS version 9.2 was used to incorporate the complex sampling design and the sampling weights. All values were weighted to adjust for the unequal selection of the sample and were calibrated to the 2010 Census characteristics by age, sex and Hispanic background in each field center's target population. Analyses also accounted for the cluster sampling and the stratification in sample selection. Frequencies and standard errors are reported to summarize the characteristics of the participants that completed the participant feedback questionnaire. Some of the demographic characteristics reported included age, sex, language preference, income, etc. These characteristics were stratified by the interaction of sex and language

preference (Table 1). Frequencies of responses for closed-ended questions, stratified by the interaction between sex and language preference, were reported for participant responses. A series of Rao-Scott F adjusted Chi-square tests for independence were conducted to examine the relationship between sex, language preference, and the items in the Participant Feedback Questionnaire. Statistical significance was determined at an alpha level of .05 for all tests (Table 2). For the analysis of the open-ended responses, inductive content analytic methods were used to develop salient themes and patterns.<sup>25</sup> A summary of themes, frequencies, and examples for the question on improving participant comfort are presented in Table 3.

### RESULTS

Of the 16,415 HCHS/SOL participants from all four field centers (Bronx, NY; Chicago, IL; Miami, FL; and San Diego, CA), 3,584, or 21.8% of all participants, completed the Participant Feedback Questionnaire at the end of their baseline examination visit. Approximately a third of the sample did not complete the questionnaire because the survey was designed and implemented later in the study. Participants from the Miami (39.27%) and San Diego (36.86%) field centers were more likely to complete the feedback questionnaire, while <8% of participants from the Bronx and Chicago field centers completed the questionnaire. Participants who completed the questionnaire compared with those who did not were similar based on selected

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demographic characteristics (eg, sex, age; data not shown). However, given that field center and background groups were collinear (eg, more individuals of Cuban heritage in Miami, more individuals of Mexican heritage in San Diego), and that there were discrepancies in completion by field centers, the Hispanic/Latino heritage background varied for those who completed the feedback questionnaire compared with those who did not. More participants from Cuban (35%) and Mexican (37%) heritage groups

completed the questionnaire compared with participants of Dominican, Central American, Puerto Rican, South American heritage, or more than one/other heritage group (completion rate ranged from 3% to 8%).

Participants' demographic data are presented in Table 1. To summarize, among females who preferred to complete the survey in Spanish, about 46% had greater than a high school degree and 65% who preferred to complete the questionnaire in English had greater than a high school education.

With regard to male participants who completed the questionnaire in Spanish, about 42% had greater than a high school education and 56% of participants who preferred to complete questionnaires in Spanish had a high school degree or higher. The majority of the participants who completed the feedback questionnaire were not US-born (80%), most were between aged 25 to 54 years (60%), and approximately 23% were between aged 55 to 74 years.

Table 2 presents the results for selected questionnaire items. Across

**Table 1. HCHS/SOL participant demographics**

|                                | Language Preference by Sex Interaction |                   |                 |                 |                 |
|--------------------------------|--|-------------------|-----------------|-----------------|-----------------|
|                                | All (N=3,584)                          | Female (2,204)    |                 | Male (N=1,380)  |                 |
|                                |  | Spanish (n=1,892) | English (n=312) | Spanish (1,093) | English (n=287) |
| Age                            |  |                   |                 |                 |                 |
| 18-24                          | 15.40 (1.05)                           | 9.02 (1.07)       | 35.76 (4.20)    | 13.53 (1.68)    | 29.44 (3.78)    |
| 25-34                          | 19.18 (1.11)                           | 16.77 (1.34)      | 25.27 (4.15)    | 17.58 (1.70)    | 28.38 (4.62)    |
| 35-44                          | 22.48 (.99)                            | 22.83 (1.17)      | 17.36 (2.84)    | 25.03 (1.92)    | 17.16 (3.08)    |
| 45-54                          | 19.09 (.79)                            | 21.47 (.96)       | 14.48 (4.74)    | 19.24 (1.18)    | 13.37 (2.13)    |
| 55-64                          | 13.81 (.80)                            | 16.55 (1.06)      | 5.44 (.96)      | 13.85 (1.02)    | 9.86 (4.46)     |
| 65-74                          | 10.03 (.74)                            | 13.36 (1.05)      | 1.68 (.73)      | 10.77 (1.43)    | 1.78 (1.20)     |
| Average years, M (SE)          | 42.34 (.44)                            | 45.60 (.54)       | 33.00 (1.29)    | 43.22 (.70)     | 34.58 (1.33)    |
| Income                         |  |                   |                 |                 |                 |
| <\$20,000                      | 47.36 (1.90)                           | 56.93 (1.87)      | 38.43 (5.08)    | 45.92 (2.38)    | 25.89 (3.81)    |
| \$20,001- 50,000               | 40.63 (1.32)                           | 36.84 (1.54)      | 46.95 (4.91)    | 42.33 (2.04)    | 43.77 (4.60)    |
| >\$50,000                      | 12.01 (1.70)                           | 6.23 (1.16)       | 14.62 (2.60)    | 11.75 (1.81)    | 30.34 (5.29)    |
| Employment status <sup>a</sup> |  |                   |                 |                 |                 |
| Retired                        | 8.71 (.72)                             | 10.68 (.97)       | 2.74 (.76)      | 9.32 (1.25)     | 4.08 (1.59)     |
| Not working                    | 43.20 (1.23)                           | 47.86 (1.50)      | 53.58 (4.44)    | 34.32 (2.15)    | 45.90(4.09)     |
| Employed                       | 48.09 (1.17)                           | 41.47 (1.42)      | 43.69 (4.47)    | 56.36 (2.15)    | 50.02 (4.01)    |
| Education                      |  |                   |                 |                 |                 |
| < High school                  | 26.16 (1.18)                           | 29.74 (1.45)      | 13.28 (2.60)    | 28.61 (2.06)    | 15.13 (2.97)    |
| High school grad               | 26.39 (1.02)                           | 23.89 (1.29)      | 21.47 (2.88)    | 29.71 (1.82)    | 28.92 (3.34)    |
| >High school                   | 47.45 (1.19)                           | 46.38 (1.64)      | 65.24 (4.00)    | 41.68 (2.02)    | 55.95 (3.86)    |
| US-born <sup>b</sup>           |  |                   |                 |                 |                 |
| No                             | 80.90 (1.44)                           | 94.04 (.82)       | 38.45 (5.25)    | 90.88 (1.34)    | 33.66 (4.47)    |
| Yes                            | 19.10 (1.44)                           | 5.96 (.82)        | 61.55 (5.25)    | 9.11 (1.34)     | 66.34 (4.47)    |
| Immigrant Generation           |  |                   |                 |                 |                 |
| 1st Immigrant generation       | 79.24 (1.52)                           | 92.33 (1.00)      | 36.96 (5.29)    | 90.05 (1.39)    | 29.45 (4.38)    |
| 2nd Immigrant generation       | 20.76 (1.52)                           | 7.67 (1.00)       | 63.04 (5.29)    | 9.95 (1.39)     | 70.55 (4.38)    |

Data are % (SE) unless otherwise indicated.

a. Employment was derived using responses to several self-reported questions. The first category represents participants who were retired and not currently employed, the second category represents participants who were not retired and not currently employed, the third category represents participants who were either employed part-time (< 35 hours/week) or employed full-time (>35 hours/week).

b. This variable groups the place of birth of the participant to the United States (50 states only) or other place of birth.

**Table 2. Participant satisfaction with exam visit experience: language preference by sex interaction<sup>a</sup>**

|   | Language Preference by Sex Interaction |              |              |        |              |              |        |
|---|--|--------------|--------------|--------|--------------|--------------|--------|
|   | Female                                 |              |              | Male   |              |              |        |
|   | All                                    | Spanish      | English      | P      | Spanish      | English      | P      |
| % (SE)  | % (SE)                                 | % (SE)       |              | % (SE) | % (SE)       |              |        |
| Enjoyed your visit to center                                    |  |              |              |        |              |              |        |
| Not at all or very little                                       | 1.39 (.34)                             | .79 (.27)    | .88 (.48)    | .0310  | 1.28 (.41)   | 4.24 (2.37)  | .0517  |
| Somewhat or a lot   | 98.61 (.34)                            | 99.21 (.27)  | 99.12 (.48)  |        | 98.72 (.41)  | 95.76 (2.37) |        |
| Study visit tests were explained clearly                        |  |              |              |        |              |              |        |
| Yes   | 99.48 (.14)                            | 99.53 (.16)  | 99.94 (.06)  | .0223  | 99.26 (.33)  | 99.66 (.25)  | .3375  |
| Rate the respect you were shown by the staff                    |  |              |              |        |              |              |        |
| Good  | 99.04 (.29)                            | 99.36 (.28)  | 98.72 (.69)  | .3061  | 99.54 (.21)  | 96.66 (2.03) | .0024  |
| Fair or poor  | .96 (.29)                              | .64 (.28)    | 1.28 (.69)   |        | .46 (.21)    | 3.34 (2.03)  |        |
| Friendliness and courtesy of staff                              |  |              |              |        |              |              |        |
| Good  | 99.18 (.18)                            | 99.01 (.29)  | 99.47 (.39)  | .4213  | 99.34 (.26)  | 99.14 (.66)  | .7618  |
| Fair or poor  | .82 (.18)                              | .99 (.29)    | .53 (.39)    |        | .66 (.26)    | .86 (.66)    |        |
| Watched informed consent DVD                                    |  |              |              |        |              |              |        |
| Yes   | 88.08 (1.06)                           | 92.27 (.80)  | 71.29 (5.37) | <.0001 | 89.76 (1.53) | 80.55 (3.46) | .0092  |
| Informed consent DVD increased understanding <sup>b</sup>       |  |              |              |        |              |              |        |
| Not at all  | 2.50 (.40)                             | 1.59 (.40)   | 4.38 (1.97)  | .0066  | 2.98 (.68)   | 3.38 (1.54)  | .4903  |
| Very little   | 4.90 (.60)                             | 5.13 (.68)   | 3.04 (1.05)  |        | 4.18 (.82)   | 7.53 (2.94)  |        |
| Somewhat  | 40.21 (1.25)                           | 40.73 (1.70) | 28.82 (4.61) |        | 42.00 (2.10) | 39.50 (5.29) |        |
| A lot   | 52.38 (1.31)                           | 52.55 (1.79) | 63.76 (4.60) |        | 50.84 (2.18) | 49.59 (4.50) |        |
| Influence of informed consent DVD on participation <sup>b</sup> |  |              |              |        |              |              |        |
| Not at all  | 8.63 (1.17)                            | 4.72 (.82)   | 22.93 (4.30) | <.0001 | 5.68 (.84)   | 24.89 (5.79) | <.0001 |
| Very little   | 8.70 (.78)                             | 7.05 (.97)   | 9.60 (2.32)  |        | 7.81 (.96)   | 17.57 (3.80) |        |
| Somewhat  | 36.82 (1.30)                           | 37.89 (1.70) | 30.66 (4.86) |        | 38.68 (2.03) | 30.40 (5.30) |        |
| A lot   | 45.85 (1.64)                           | 50.34 (1.70) | 36.81 (4.09) |        | 47.83 (2.18) | 27.14 (4.09) |        |
| Expectation for length of time of examination                   |  |              |              |        |              |              |        |
| Shorter than expected   | 30.51 (1.28)                           | 32.23 (1.68) | 32.15 (5.41) | .0027  | 31.30 (1.98) | 20.80 (3.52) | .0016  |
| What you expected   | 54.31 (1.29)                           | 55.24 (1.44) | 43.13 (4.39) |        | 56.01 (2.29) | 54.09 (4.40) |        |
| Longer than expected  | 15.17 (.92)                            | 12.54 (.95)  | 24.72 (4.06) |        | 12.69 (1.40) | 25.11 (4.64) |        |

a. Differences between language within sex were examined using chi-square tests.

b. Includes only those who stated to have watched the informed consent DVD.

both sexes and language, most participants (99%) liked their visit to the field center either somewhat or a lot compared with not at all or very little (1.39%). Almost all participants (99%) felt that the baseline examination tests were explained clearly, rated staff as good in terms of respect, and friendliness and courtesy (99%).

Regardless of sex, more Spanish-speaking participants (female=92%, male=90%) watched the informed consent DVD compared with English speakers (female=71%, male=81%).

However, more English-speaking females found that the DVD about informed consent helped their understanding of the study “a lot” (64%) compared with Spanish-speaking females (53%). Yet, more Spanish-speaking participants felt that the informed consent DVD influenced their decision to participate in the study “a lot” (female=50%, male=48%).

Participants were asked to rate the length of the examination visit by choosing from three possible responses (shorter than expected, what

was expected or longer than expected). Of those participants who preferred English, 24% of female participants and 25% of male participants felt that the baseline examination was longer than expected compared with both Spanish-speaking females (13%) and males (13%). However, regardless of sex and language preference, 54% of the participants reported the length of the examination exactly as it was expected; while fewer male English-speakers reported that the visit was shorter than expected (21%).

**Participant Feedback Assessed through Open-ended Questions**

Of the 3,584 participants who completed the Participant Feedback Questionnaire, 229 (6%) provided suggestions for improving the HCHS/SOL visit. Themes between and within participant responses to improve their study visit are summarized in Table 3. A total of two coders and percent agreement was used to calculate inter-coder agreement. Agreement between coders was 95%, which is considered an acceptable level of agreement.<sup>21</sup> In cases where there was disagreement, the coders discussed the themes and were able to reach an agreement. Of the total 213 responses coded, 16 responses were determined to be low frequency responses or did not fit the themes identified in this study. Low frequency suggestions for improving the HCHS/SOL visit included comments such as “Have someone take care of children,” “We should always try to improve.” The top three themes for improving the overall experience were categorized as: 1) overall satisfaction (46%); 2) operations/flow (22%); and 3) length of examination visit (13%). The comments concerning operations or study flow were primarily regarding the sequence of the procedures involved as part of the baseline examination, and suggesting the completion of the visit in two parts. The length of the baseline examination visit generally pertained to suggestions from participants such as having fewer questions in the questionnaires and shortening the time in the center or sending the paperwork prior to the visit. Feedback provided by participants to im-

**Table 3. Participant suggestions for improving HCHS/SOL experience**

| Overall Theme        | n (%), (N=213) | Examples  |
|----------------------|----------------|---|
| Operations/flow      | 46 (21.5)      | Do exam in 2 parts; draw blood first, breaks between exams, only 1 blood draw, anything to do with exam procedures. |
| Setting environment  | 6 (2.8)        | Have a TV, have magazines, clinic too cold, more chairs in waiting room, music.                                     |
| Food/beverage        | 9 (4.2)        | Better food, more food, snack after fasting, food for individuals with diabetes.                                    |
| Overall satisfaction | 98 (46)        | Very friendly staff, should have more visits, everyone was organized, staff created a sense of trust.               |
| Dissatisfaction      | 23 (10.8)      | Staff was rude, more eye contact, phlebotomist need to be more careful, staff needs to be clearer.                  |
| Time burden          | 27 (12.7)      | Faster, shorter visits, paperwork sent home.  |
| Additional tests     | 4 (1.9)        | Participants requested that SOL include additional exams (eg, vision, head scans, etc.).                            |

prove the study visit experience was largely reported for environmental aspects such as the room temperature of the waiting room and provisions of hot beverages and snacks.

Regarding the levels of satisfaction with the visit, the majority of the participants’ comments expressed satisfaction with different aspects of the study (eg, staff interaction [“Everyone was really (or very) professional”], overall experience: [“It was a good experience”]). This is aligned with the quantitative analyses that suggests that participants were satisfied with the study.

**DISCUSSION**

Research findings on the factors that may facilitate or hinder recruitment and retention of minorities in longitudinal cohort studies are limited, particularly among diverse Hispanic/Latino heritage groups. Even fewer studies have published specific strategies that examine participant satisfaction regarding study recruitment, retention and follow-up procedures,

which may be pivotal to inform participation strategies among minority populations such as Hispanic/Latino.

Several challenges arose in the completion of the Participant Feedback Questionnaire administered at the end of the study baseline examination visit. The primary reasons for opting out of the questionnaire were related to time conflicts and time burden in addition to the average 7.5 hour baseline examination visit. Also, the voluntary nature of the feedback questionnaire administration method (eg, questionnaire not included as part of the minimum battery of questionnaires) did not allow for standardization in terms of implementing the survey across field centers. It is possible that there was some bias in the completion of the questionnaire, whereby some participants who were either very satisfied or dissatisfied were more willing to complete the questionnaire. The limited disproportional sample size from two specific field centers led to the lack of representation across the Hispanic/Latino heritage groups restricting the generalizability to all Hispanics/Latinos in

the target population. Lastly, due to delays in its development, data collection using the feedback questionnaire was introduced almost half way into the study. This contributed to the small sample size of total Participant Feedback Questionnaires completed by participants. Additionally, because participants completed the questionnaire at different times and environments, it is possible that someone other than the participant completed the

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*Results from our study are significant to develop and improve effective linguistic and culturally adapted recruitment and retention strategies among minority groups in research studies.*

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questionnaire. Therefore, due to these limitations presented above, findings from this study may be biased and not representative of the entire cohort.

Although there was a general lack of standardization of the administration of the Participant Feedback Questionnaire, each field center contributed valuable findings. The diverse and large sample size of the HCHS/SOL presented a unique opportunity to inform future HCHS/SOL study examination visit practices for this study. These findings provide insights about participants' satisfaction in research studies and may aid future studies in the development of recruitment

and retention efforts for inclusion of Hispanic/Latino heritage groups.

The HCHS/SOL remains the largest and most comprehensive contemporary epidemiological study conducted among Hispanic/Latino heritage groups and provides an exceptional opportunity to assess participants' satisfaction of the study at multiple levels. A unique attribute of HCHS/SOL is that most study recruitment and examination staff reside within the target study communities, are representative of the same Hispanic/Latino heritage group as those being recruited, and have previous experience in working with the Hispanic/Latino population in similar studies.

Results from our study are significant to develop and improve effective linguistic and culturally adapted recruitment and retention strategies among minority groups in research studies. Among Hispanics/Latinos, the results of the HCHS/SOL study suggest that participants were highly satisfied with their examination visit experience. These findings may be due to the study's awareness and emphasis of relevant cultural values (ie, *respeto*, *familismo*, *personalismo*) and cultural tailoring of each phase of the study and procedures, which contributed to overall participant satisfaction. The use of bilingual/bicultural staff further supported the cultural appropriateness of the study. HCHS/SOL staff treatment of and interactions with participants fostered a sense of trust for the study which positively influenced the overall examination visit experience among participants. Moreover, by viewing the informed consent DVD, participants in the study increased

their understanding of the prevalent health issues affecting Hispanic/Latino heritage groups and their valued contribution to science. These factors may have contributed to an average response rate of 86% for follow-up years 1 - 4. To determine how these factors influence future participation, it is important to continue evaluating satisfaction to predict retention rates.

Based on this research we suggest a few strategies for improving the recruitment and retention of participants: 1) culturally tailor each phase of the study, including the use of bilingual and bicultural staff representative of the community being studied; 2) create an iterative process to gather feedback from participants throughout the study to maintain or improve satisfaction; 3) develop tools (eg, recruitment and consent DVDs) to help participants better understand the study purpose, importance, and procedures; 4) collaborate with stakeholders (eg, community representatives) to develop and refine the study materials (eg, consent form, recruitment). Our protocols, manuals, DVD tools have been made available to the general public on the study website: <https://www2.csc.unc.edu/hchs/>. Using these strategies will help to improve the recruitment and retention of ethnic minorities in research studies.

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### CONFLICT OF INTEREST

No conflicts of interest to report.

### AUTHOR CONTRIBUTIONS

Research concept and design: Talavera, Buelna, Espinoza Giacinto, Castañeda, Giachello, Hernández, Rodríguez, Sanchez, Perreira; Acquisition of data: Talavera, Buelna, Castañeda, Crespo-Figueroa, Hernández, Rodríguez, de los Angeles Abreu, Sanchez, Perreira; Data analysis and interpretation: Talavera, Buelna, Espinoza Giacinto, Castañeda, Perreira; Manuscript draft: Talavera, Buelna, Espinoza Giacinto, Castañeda, Giachello, Crespo-Figueroa, Hernández, Rodríguez, de los Angeles Abreu, Sanchez, Perreira; Statistical expertise: Buelna, Espinoza Giacinto, Castañeda, Perreira; Acquisition of funding: Perreira; Administrative: Talavera, Espinoza Giacinto, Castañeda, Giachello, Crespo-Figueroa, Hernández, Rodríguez, de los Angeles Abreu, Sanchez, Perreira; Supervision: Talavera, Giachello, Hernández, Rodríguez, Perreira

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