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Minorities Remain Underrepresented in HIV/AIDS Research Despite Access to Clinical Trials

Jose R. Castillo-Mancilla, MD¹, Susan E. Cohn, MD, MPH², Supriya Krishnan, DSc³, Michelle Cespedes, MD, MS⁴, Michelle Floris-Moore, MD, MS⁵, Gail Schulte⁶, Gregory Pavlov⁷, Donna Mildvan, MD⁸, Kimberly Y. Smith, MD⁹, and the ACTG Underrepresented Populations Survey Group

¹University of Colorado-AMC, Aurora, CO

²Northwestern University, Feinberg School of Medicine, Chicago, IL

³Center for Biostatistics in AIDS Research, Harvard School of Public Health, Boston, MA

⁴New York University School of Medicine, New York, NY

⁵University of North Carolina School of Medicine, Chapel Hill, NC

⁶Social and Scientific Systems, Silver Spring, MD

⁷Frontier Science & Technology Research Foundation, Inc, Amherst, NY

⁸Beth Israel Medical Center, New York, NY

⁹Rush University Medical Center, Chicago, IL

Abstract

Background—The reasons for minority underrepresentation in HIV/AIDS clinical trials remain unclear. We aimed to evaluate the knowledge, experience and factors that influence minority participation in HIV/AIDS studies in the US.

Methods—An anonymous, bilingual, self-administered survey on study participation was given to HIV-infected adults attending AIDS Clinical Trials Group-affiliated clinics in the US and Puerto Rico. Chi-square tests were used to evaluate differences by race/first language/level of education. Logistic regression was used to estimate odds ratio (OR) and 95% confidence interval (CI) for factors associated with being talked to about participation in a study.

Results—We analyzed 2,175 complete surveys (221 in Spanish). Among respondents, 31% were White, 40% black/African American (AA) and 21% Hispanic. The overall rate of previous participation in any HIV/AIDS study was 48%. Hispanics were less likely to know about studies compared to whites and AAs (67% vs. 74% and 76%; $p < 0.001$). Compared to whites, AAs and Hispanics were less likely to have been talked to about participating in a study (76% vs. 67% and

Corresponding Author: Jose R. Castillo-Mancilla, MD, Division of Infectious Diseases, University of Colorado-AMC, 1635 Aurora Ct, B163, Aurora, CO 80045, Phone (720) 848 0821, Fax (720) 848 0192, jose.castillo-mancilla@ucdenver.edu.

Conflicts of Interest:

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67%; $p < 0.001$). The OR for being talked to about participating in a study was 0.65 (95% CI: 0.52–0.81) for AAs and 0.65 (95% CI: 0.49–0.85) for Hispanics, compared to whites. AAs and Hispanics were more likely to state that studies were not friendly to their race (17% and 10% vs. 4%; $p < 0.001$).

Conclusions—Minorities continue to face barriers for HIV/AIDS trial participation, even when clinical research is available. Enrollment strategies should better target minorities to improve recruitment in HIV/AIDS research.

Keywords

Minority; Research Participation; Underrepresented; HIV; Clinical Trials; AIDS

Background

Despite being disproportionately affected by the human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) in the United States (US), minorities continue to be underrepresented in HIV/AIDS clinical trials. This critical issue limits our understanding of how applicable treatment outcomes are to the general population and lessens the potential benefits of clinical research to all members of society.^{1,2,3,4} The reasons for minority underrepresentation in clinical research are varied and complex; some of them are common to all minority groups (i.e. lack of information and access to trials, provider bias on adequacy of trial enrollment, competing family and financial priorities, low levels of education, lack of health insurance and negative family and community opinions about research),^{3,5} while others are specific to a certain minority groups (i.e. mistrust from African-American community, language barriers in Hispanic immigrants).^{4,6,7} Many of the studies that have evaluated the reasons that prevent minorities from enrolling in HIV/AIDS-related clinical trials have focused on a single site^{1,8} or have studied populations with limited access to clinical trials.⁴ Thus, there is a critical need for further research to understand the knowledge and attitudes that HIV-infected minorities in the US have towards participation in HIV/AIDS clinical trials.

The AIDS Clinical Trials Group (ACTG) is a long-standing network of domestic and international research sites that conduct HIV/AIDS clinical trials.⁹ It includes a network of 47 domestic sites located in all 4 US regions (Northeast, South, Midwest and West) and Puerto Rico. In many of these settings, clinical care and research facilities are co-located, while they may be separate in others. These sites include University-based HIV clinics, Public Hospital clinics and Community Health Centers, with a varied payor mix of insured/uninsured patients according to the specific site. The primary objective of our study was to describe and evaluate the knowledge, experience and factors that influence minority participation in HIV/AIDS clinical trials among patients attending ACTG-affiliated clinical sites. To address our objective we conducted a self-administered survey on HIV/AIDS trial participation at clinical centers associated with the ACTG in the US and Puerto Rico.

Methods

Survey distribution and content

The ACTG Underrepresented Populations Committee (UPC) developed the survey, which was available both in English and Spanish (Appendix). The survey was developed *de novo* and piloted in 5 ACTG sites covering 4 geographical areas of the US. In this pilot, a total of 100 surveys were distributed to the sites, of which 93 were completed and returned for analysis. All 47 domestic ACTG sites were then invited to participate in the survey through an e-mail memorandum from the ACTG Executive Committee Leadership. Site participation was completely voluntary. Participating sites were sent a total of 60 surveys in English and 12 in Spanish, but the number of Spanish surveys sent could be increased upon a specific site request. The sites were asked to distribute the surveys over a period of five months, with a goal of obtaining 50 completed surveys per site. All sites obtained the approval from their local institutional review board before initiating the study.

HIV-infected individuals who were 18 years and older and were attending the clinic or research center for regular medical care were approached for participation by the ACTG personnel (research nurse or research coordinator) or clinic staff. Sites were encouraged to over represent women and minorities (when feasible) to allow for a diverse sample that would be more representative of the demographics of the HIV epidemic in the US. Evidence of HIV infection in the medical record was required for participation. The survey was an anonymous, 7-page questionnaire written at a 6th grade reading level, which spanned 34 items in 3 categories: a) demographics; b) participation in and perceptions about clinical trials, and; c) behaviors. If an individual agreed to participate, she/he was given a paper copy of the survey and a letter-sized envelope labeled with a number. The questionnaire clearly stated that the information from the survey was strictly confidential and that the answers would not be shared with the participant's health care provider(s). The participant then completed the survey confidentially, usually in a private room. Participants could receive assistance if they had problems reading the survey or if they had any questions regarding the survey. Once completed, the participants placed the completed survey inside of the provided envelope, sealed it, and gave it to the research nurse or coordinator. Sites were provided with pre-addressed return shipping labels and were requested to return all completed surveys to the ACTG Data Management Center by the end of the enrollment period. Sites that did not adhere to this protocol were excluded from the analysis.

Statistical analysis

Chi-square tests were used to evaluate differences in responses to survey questions by race, first language and level of education. No adjustments were made for multiple comparisons in this descriptive study (some p-values could have resulted to be significant by chance). Logistic regression was used to estimate odds ratios (OR) and 95% confidence intervals (CI) for demographic and behavioral factors associated with ever being talked to about participation in a clinical trial. Demographic factors included age, sex, race, education and first language. Behavioral factors included tobacco use, alcohol use and substance use. Univariate models were used to assess the unadjusted ORs between the factors stated above and being talked to about participating in a clinical trial. Variable that were significant

($p < 0.05$) at a univariate level were added to the multivariable model. Age, sex and first language were included in the multivariable model regardless of their p -value. For all other variables, only those with $p < 0.05$ were retained in the multivariable model. All analyses were performed using SAS version 9.2 (SAS Institute Inc., Cary, NC).

Race was determined according to participant self-identification as white, black/African American, Hispanic/Latino, Asian, Native American, American Indian, Alaska Native, Native Hawaiian/other Pacific Islander or other. For the adjudication of race among individuals who selected two races, Hispanic and any other race was coded as “Hispanic”, black/African American and any other race (other than Hispanic) was coded as “black/African American”, white and any other race (other than Hispanic or black/African American) was coded as “white”. Respondents who checked 3 or more races or who added in another race category, without having also checked black/African American or Hispanic/Latino, were coded as “Other/Mixed race.”

Results

We distributed surveys to a total of 47 sites and received 2,263 completed surveys from 42 sites, 2,175 of which were included in the analysis (five sites did not return any surveys). We excluded 88 surveys from two sites due to protocol violations. Of the 2,175 surveys, 221 surveys were in Spanish. The demographic characteristics of the 2,175 patients who responded to the analyzed surveys are shown in Table 1.

Knowledge, Interest and Participation in HIV/AIDS clinical trials

No differences between male and female participants were observed in any of the evaluated survey questions. The overall rate of previous participation in any HIV/AIDS clinical trial among all individuals surveyed was 48% for both men and women. In Table 2 we present results on the knowledge about availability, intention to participate, being approached for participation, attempted participation, and previous active participation in HIV/AIDS clinical trials according to race, first language and level of education. Compared to whites and black/African-Americans (AAs), Hispanics were less likely to know about available studies. AAs and Hispanics were less likely to have been talked to about participating, have thought about participating, have tried to enroll and have actively participated in a study when compared to whites. Subjects who identified Spanish as their first language were less likely to know about available studies compared to English speakers, but did not show significant differences in any of the other questions in this section.

The differences in trial interest and participation according to level of education were also evaluated. Participants who had higher levels of education (some college/completed college/graduate school) were more likely to know about, to consider participating, to have been told about, to have tried to participate or have actively participated in a clinical trial compared to individuals with a high school education or less. Similarly, in the multivariate analysis, individuals with some college/technical school and college graduates were more likely to have been approached to participate in a clinical trial (adjusted OR 1.57; CI:1.06–2.33 and 1.68; CI:1.12–2.51, respectively)

Experience during previous participation in HIV/AIDS clinical trials

Table 3 shows the experiences of 1,294 individuals who reported previous participation in an HIV/AIDS clinical trial (defined as a combination of “tried to be in a study” and “ever been in a study”). Hispanics were more likely to believe that participating in a trial made them healthier when compared to whites and AAs. This was also observed when we compared Spanish to English speakers and individuals with an elementary school education to more educated patients. Spanish speakers were also more likely to believe that participating in a clinical trial helped them get better medical care, as were individuals with more than a high school education. When compared to Hispanics and AAs, whites were more likely to report that participating in a study made them feel like they were helping others, which was also observed when we compared highly educated participants to those with lower levels of education. Overall, a small proportion of individuals (<5%) stated that participating in an HIV/AIDS clinical trial made them feel worse or made them feel less connected with their primary care provider (data not shown).

Factors that influence participation in HIV/AIDS clinical trials

Factors that would encourage or prevent individuals from enrolling in a research study, regardless of whether they have participated or not in the past, are presented in Table 4. Whites and AAs were more likely to enroll in a clinical trial to help fight HIV/AIDS when compared to Hispanics, but Hispanics and AAs, and Spanish speakers were more likely to enroll in a study to get better healthcare when compared to whites and English speakers, respectively. AAs and Hispanics reported that they would be more willing to enroll in a study to represent their race when compared to whites. Spanish speakers were less interested in enrolling in a study to help fight HIV/AIDS or to obtain monetary compensation compared to English speakers. Individuals with a college/post-graduate education were more likely to participate in a clinical trial to help fight HIV/AIDS compared to individuals with an elementary school education.

Hispanics and AAs were more likely to state that studies were not friendly to their race and were more likely to avoid participation because they did not understand clinical trials when compared to whites. This was also observed in high school graduates, who reported not understanding the studies more frequently when compared to college/post-graduates. Hispanics and AAs were more concerned about a breach in confidentiality and of being a “guinea pig”, while white participants were more worried about getting placebo as the main reason to avoid a clinical trial. Overall, only a small proportion of individuals reported religious beliefs as the reason to avoid clinical trial participation (data not shown).

The multivariate analysis of factors associated with being talked to about participation in an HIV/AIDS clinical trial is presented in Table 5. The unadjusted OR for being talked to about participation in a study for individuals with some college/technical school or with a college/post-graduate degree were 1.67 (95% CI: 1.15, 2.43) and 1.89 (95% CI: 1.29–2.77), respectively, when compared to individuals with an elementary school education. This remained significant after adjusting for age, sex, race, first language and active tobacco use. Minority racial background was also associated with lower OR of being talked to about participation in a study when compared to white race; the unadjusted OR was 0.65 (95% CI:

0.52–0.81) for AAs and 0.65 (95% CI: 0.49–0.85) for Hispanics, which remained significant for AAs after adjusting for age, sex, education, first language and active tobacco use.

Discussion

In this study, we performed an anonymous cross-sectional survey of HIV-infected patients at ACTG clinical sites. Our results demonstrate a moderately robust (48%) rate of previous participation in any HIV/AIDS trial in this setting. However, it also reveals persistent minority underrepresentation in HIV research, even in an environment in which knowledge on the availability of HIV clinical trials is expected to be higher than the general HIV-infected population. Enrollment in a clinical trial is a process that requires active roles by both patients and researchers at multiple steps, from the potential participant's awareness and intention to join a study to the researcher's function as an unbiased enrollment facilitator for all possible participants.^{8,10,11,12} In our data, the underrepresentation of racial minorities was evident at all levels of the research participation continuum: knowledge of trials, intention to participate, being approached by research team, effort to enroll, and successful enrollment. Our findings are consistent with results from a CDC-based study by Sullivan, et al, which found an OR of 0.6 for trial participation in black and Hispanic men compared to white men among 5,010 interviewees in 15 US states.⁴ In that study, overall participation of HIV-infected individuals was 17% among men and 15% among women, which is similar to the 14% clinical trial participation in a representative sample of all HIV infected patients in care within the US previously reported by Gifford, *et al*,² but low when compared to the 48% found in our survey. However, it is important to emphasize that the populations evaluated in these studies are not directly comparable to our population. While we evaluated HIV-infected individuals accessing routine medical care at an ACTG-affiliated site, Sullivan, *et al* assessed adults with HIV/AIDS who participated in a behavioral surveillance study and the study by Gifford, *et al* analyzed trial participation in individuals enrolled in the HIV Cost and Services Utilization Study, which constituted a representative sample of HIV-infected patients receiving medical care. Limited knowledge of available studies is the first barrier that prevents trial enrollment. Hispanics and AAs have historically been reported to have less knowledge about the clinical trials for which they may be eligible.^{8,13} In some instances, these limitations can be overcome by building multidisciplinary teams and strategies aimed at fulfilling the needs of specific communities, but their general applicability has yet to be evaluated.^{3,5,10,12}

In addition to the limited knowledge about clinical trials, mistrust and fear towards medical research can negatively influence study participation among minorities.^{1,7,14} Some of this fear is rooted in historical events where fundamental ethical principles were violated in research activities involving racial minorities,^{15,16,17} resulting in negative community attitudes towards medical research. An example of this mistrust could be observed in our study by the proportion of AAs and Hispanics who stated that studies were “not friendly” to their race, and also by the proportion of these minority individuals who were concerned about being a “guinea pig” or having their personal information disclosed without their consent, which is consistent with previous observations in other studies.^{4,13} Importantly, when previous trial participants were asked about their experience in an HIV/AIDS study, we found no difference in the proportion of AAs or Hispanics vs. whites who reported

negative feelings. This serves as a clear example of the disconnect between the preconceived negative notions about medical research and the actual benefits of trial participation among minority groups, a concern that requires intensive intervention from the research community to improve minority participation.

Low levels of education and inadequate health literacy have been associated with underrepresentation in clinical research.^{2,18} This association with education levels was evident in our study by the proportion of individuals with a high school education or less who were not aware about clinical trials and had never been approached to participate, thought of participating, tried to participate or had participated in an HIV/AIDS study. Language barriers, limited healthcare utilization, and an unstable immigration status may also limit minority knowledge and intention to participate in clinical trials.^{2,19,20} Although our study did not identify significant differences in participation in HIV/AIDS trials according to first language (English vs. Spanish), we did observe a lack of knowledge about available studies among Spanish speakers. Interestingly, Spanish speakers were not more likely to report that they would avoid trial participation because they did not understand the studies, which could be explained by the benefits of having a bilingual staff and informed consents in Spanish available at many ACTG sites.

Research staff perceptions on minority participation are also a major factor that influence trial enrollment. This could partially explain the small proportion of minority patients that reported having ever been approached to participate in an HIV/AIDS clinical trial (66% AAs and 73% Hispanics vs. 75% whites, $p < 0.001$), which remained significant in the multivariate analysis and is consistent with previous observations in HIV/AIDS and non-HIV/AIDS studies.^{6,21,22} In a previous ACTG-based study, King, *et al*, showed that research personnel could be biased against approaching AAs, Hispanics and non-English speakers into HIV/AIDS clinical trials because these individuals may be perceived as being less interested in study participation and also less likely to successfully enroll and stay in the study.²¹ Similarly, Wendler, *et al*, identified substantial differences by race and ethnicity in the number of individuals invited to participate in clinical trials (some of which included HIV infection).⁶ Among some of the reasons that could explain this bias are racial and gender disparities that exist between the HIV/AIDS-affected population and the research personnel, concerns for study and medication non-compliance, language barriers that can exist between patients and researchers and some inaccurate preconceived notions that investigators may have about racial minorities.^{23,24} This bias in recruitment has also been observed among medical providers of HIV care, who are usually the main source of referrals for research studies.^{3,25} Increasing minority participation in HIV/AIDS research requires increased outreach for inclusion of underrepresented populations and assurance of access to health research for all individuals, rather than a radical modification of minority attitudes.⁶ The racial and ethnic diversification of the research and medical staff,^{26,27} in addition to the engagement of previous minority study participants (and their communities), could prove a useful strategy with a beneficial impact in minority recruitment and retention in clinical trials, particularly if the research experience has been mostly positive, as found in our study.

We found that a majority of Hispanics and Spanish speakers believed that participating in a study had made them healthier. This is an interesting finding that was also supported by the

large proportion of Hispanics and Spanish speakers who identified the possibility of obtaining “better healthcare” as a main reason to participate in a study. According to data from the Pew Hispanic Center, approximately 31% of Hispanics in the US do not have health insurance, which is almost double of the overall 16% of Americans without health insurance.²⁸ Participating in a clinical trial could be the only viable option for some HIV-infected individuals to access any healthcare and life-saving medications and offers a unique opportunity for newer, more effective strategies aimed at increasing enrollment in these marginalized populations. Therefore, promoting clinical trial participation as an overall health benefit and opportunity for improved medical care could be used as a successful strategy to increase the enrollment of these disadvantaged minorities.

Our study has some limitations. First, self-administered HIV/AIDS-related surveys carry an inherent risk of reporting bias, barriers in communication, inaccurate disclosure of behaviors and overestimation of favorable responses.²⁹ Second, there may be overlap between ethnic group, first language and level of education. Third, we excluded a small number of participants in the “other/mixed” race category for whom we were unable to adjudicate race due to the very small number of individuals in each group. Fourth, we actively targeted minorities and women from within a population of HIV-infected patients being cared for at ACTG sites that actively recruit for clinical trials, which carries the potential for selection bias. While we understand that patients at these research-affiliated clinical sites may not be representative of the general HIV-infected population and would be more likely to know about HIV/AIDS clinical trials, we believe our study presents unique and novel results because it identified notable racial disparities, even in a setting where all individuals had direct access to research studies.

Conclusion

Representation of all racial and social backgrounds in HIV/AIDS clinical trials is important to better understand treatment outcomes and identify issues that may be unique to some populations. Our study describes underrepresentation of minorities in HIV-related studies that may be promoted by a combination of the individual’s pre-conceived fear and mistrust of medical research, the research staff biases related to enrollment of marginalized populations and the limitations that the studies can impose to the inclusion of minority individuals. Researchers should enhance their efforts to minimize research participation disparities and improve recruitment from all ethnic and racial groups who are affected by HIV/AIDS in the US.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Demographics of survey participants (N=2,175).

Characteristic	N (%)
Race	
White	677 (31)
African- American	871 (40)
Hispanic	445 (20)
Other/Mixed	125 (6)
No response	57 (3)
Gender	
Male	1,546 (71)
Female	573 (26)
Transgender (MTF)	13 (1)
No response	43 (2)
First Language	
English	1,748 (80)
Spanish	292 (13)
Other	31 (1)
No response	104 (5)
Level of Education	
Elementary	153 (7)
High School	678 (31)
Some College/Technical	672 (31)
College/Graduate	618 (28)
No response	54 (2)
Employment *	
Not employed	618 (28)
Part-time employment	296 (14)
Full-time employment	608 (28)
Homemaker	89 (4)
Disabled	604 (28)
Student	110 (5)
Retired	104 (5)
Tobacco use (any within last year)	
	873 (40)
Alcohol use (any within last month)	
	865 (40)
5 drinks in a row at least once	636 (29)
Illicit drug use (any within last year)	
Marijuana	553 (25)

Characteristic	N (%)
Other [‡]	256 (12)

MTF=Male-to-female.

* Proportions are not mutually exclusive and may add to >100%.

[‡] Includes cocaine, heroin and amphetamines.

Table 2
 Knowledge and participation in HIV/AIDS clinical trials according to race, first language and level of education.

	Race (N=1,993) [§]			Language (N=2,040) [‡]			Education (N=2,121) [‡]			p value*		
	White (N=677)	African American (N=871)	Hispanic (N=445)	p value*	English (N=1,748)	Spanish (N=292)	p value*	Elementary (N=153)	High School (N=678)		Some College/Technical (N=672)	College/Graduate (N=618)
Know about available studies?	479 (71%)	590 (68%)	263 (59%)	<0.001	1,193 (68%)	172 (59%)	0.02	85 (55%)	421 (62%)	455 (68%)	454 (73%)	0.02
Thought about being in a study?	551 (82%)	609 (70%)	323 (74%)	<0.001	1,307 (75%)	210 (72%)	0.2	107 (70%)	458 (67%)	519 (77%)	499 (81%)	<.001
Talked to about being in a study?	509 (75%)	576 (66%)	289 (73%)	<0.001	1,220 (70%)	188 (64%)	0.3	90 (59%)	435 (64%)	481 (72%)	458 (74%)	<.001
Tried to be in a study?	448 (66%)	438 (50%)	231 (52%)	<0.001	995 (57%)	159 (55%)	0.9	81 (53%)	329 (48%)	396 (59%)	392 (63%)	<.001
Ever been in a study?	396 (58%)	361 (42%)	200 (45%)	<0.001	847 (48%)	141 (48%)	0.3	63 (41%)	269 (40%)	350 (52%)	334 (54%)	<.001

* Chi Square test.

[§] Excluded individuals who responded other race (N=102), mixed race (N=23) or had no response (N=57).

[‡] Excluded individuals who responded other language (N=31) or had no response (N=104).

[‡] Excluded individuals who had no response (N=54).

Table 3

Experience in HIV/AIDS clinical trials among previous participants according to race, first language and level of education.

	Race (N=1,195) [§]			Language (N=1,233) [†]			Education (N=1,278) [‡]			p value*	
	White (N=461)	African-American (N=473)	Hispanic (N=261)	English (N=1,053)	Spanish (N=180)	p value*	Elementary (N=92)	High School (N=362)	Some College/Technical (N=416)		College/Graduate (N=408)
Study made me healthier	220 (48%)	208 (44%)	155 (59%)	488 (46%)	120 (67%)	<.001	59 (64%)	157 (43%)	199 (48%)	214 (52%)	0.002
Study took too much time	23 (5%)	12 (3%)	10 (4%)	40 (4%)	8 (4%)	0.144	1 (1%)	12 (3%)	18 (4%)	19 (5%)	0.378
I learned about HIV/AIDS	252 (55%)	277 (59%)	156 (60%)	589 (56%)	113 (63%)	0.322	54 (59%)	206 (57%)	242 (58%)	221 (54%)	0.664
I felt like a guinea pig	24 (5%)	19 (4%)	16 (6%)	51 (5%)	11 (6%)	0.424	5 (5%)	22 (6%)	19 (5%)	18 (4%)	0.710
Got better medical help	205 (44%)	187 (40%)	121 (46%)	440 (42%)	93 (52%)	0.141	35 (38%)	122 (34%)	193 (46%)	199 (49%)	<.001
I felt like I was helping others	329 (71%)	263 (56%)	147 (56%)	665 (63%)	103 (57%)	<.001	40 (43%)	193 (53%)	287 (69%)	271 (66%)	<.001
Logistical challenges	21 (5%)	8 (2%)	8 (3%)	32 (3%)	8 (4%)	0.041	3 (3%)	9 (2%)	13 (3%)	14 (3%)	0.894
Study help me feel in control	242 (52%)	239 (51%)	149 (57%)	537 (51%)	114 (63%)	0.232	53 (58%)	172 (48%)	224 (54%)	221 (54%)	0.149

^aN=Individuals who responded “Yes” to the questions “Have you ever tried to be in an HIV/AIDS study?” and/or “Have you ever been in an HIV/AIDS study?”

* Chi Square test.

[§] Excluded individuals who responded other race (N=62), mixed race (N=16) or had no response (N=21).

[†] Excluded individuals who responded other language (N=12) or had no response (N=49).

[‡] Excluded individuals who had no response (N=16).

Table 4

Factors that influence HIV/AIDS clinical trial participation according to race, first language and level of education.

	Race (N=1,993) [§]			Language (N=2,040) [‡]			Education (N=2,121) [‡]					
	White (N=677)	African- American (N=871)	Hispanic (N=445)	P value*	English (N=1,748)	Spanish (N=292)	P value*	Elementary (N=153)	High School (N=678)	College/Technical (N=672)	Some College/Graduate (N=618)	P value*
Reasons to be in study												
Help fight HIV/AIDS	582 (86%)	721 (83%)	320 (72%)	<0.001	1,463 (84%)	204 (70%)	<0.001	97 (63%)	538 (79%)	578 (86%)	519 (84%)	<0.001
Better Healthcare	221 (33%)	349 (40%)	215 (48%)	<0.001	633 (36%)	166 (57%)	<0.001	67 (44%)	236 (35%)	275 (41%)	251 (41%)	0.04
Might get money	212(31%)	277 (32%)	102 (23%)	0.002	562 (32%)	55 (19%)	<0.001	36 (24%)	209 (31%)	235 (35%)	151 (24%)	<0.001
Learn about HIV/AIDS	349 (52%)	509 (58%)	235 (53%)	0.012	951 (54%)	169 (58%)	0.3	84 (55%)	356 (53%)	395 (59%)	319 (52%)	0.04
Get medications	211 (31%)	232 (27%)	116 (26%)	0.08	494 (28%)	91 (31%)	0.3	46 (30%)	166 (24%)	191 (28%)	203 (33%)	0.01
Represent gender	120 (18%)	269 (31%)	116 (26%)	<0.001	435 (25%)	90 (31%)	0.03	52 (34%)	168 (25%)	188 (28%)	125 (20%)	<0.001
Represent race	71 (10%)	311 (36%)	140 (31%)	<0.001	429 (25%)	108 (37%)	<0.001	52 (34%)	176 (26%)	190 (28%)	139 (22%)	0.01
MD recommended	315 (47%)	281 (32%)	150 (34%)	<0.001	667 (38%)	110 (38%)	0.9	57 (37%)	220 (32%)	271 (40%)	247 (40%)	0.01
Family/friend recommendation	71 (10%)	113 (13%)	45 (10%)	0.2	197 (11%)	38 (13%)	0.4	25 (16%)	89 (13%)	70 (10%)	59 (10%)	0.04
Reasons to avoid study												
Not friendly to my race	27 (4%)	147 (17%)	44 (10%)	<0.001	197 (11%)	26 (9%)	0.2	9 (6%)	78 (12%)	91 (14%)	55 (9%)	0.01
Not friendly to my gender	31 (5%)	94 (11%)	30 (7%)	<0.001	145 (8%)	18 (6%)	0.2	5 (3%)	50 (7%)	69 (10%)	43 (7%)	0.01
Not friendly if I use drugs	30 (4%)	102 (12%)	26 (6%)	<0.001	150 (9%)	17 (6%)	0.1	10 (7%)	63 (9%)	63 (9%)	37 (6%)	0.07
Not friendly if I use alcohol	32 (5%)	74 (8%)	22 (5%)	0.004	122 (7%)	17 (6%)	0.5	9 (6%)	50 (7%)	53 (8%)	30 (5%)	0.1
Worry of being hurt	147 (22%)	201 (23%)	99 (22%)	0.8	407 (23%)	60 (21%)	0.3	21 (14%)	142 (21%)	178 (26%)	139 (22%)	0.003
Worry about placebo	163 (24%)	96 (11%)	65 (15%)	<0.001	296 (17%)	41 (14%)	0.2	16 (10%)	57 (8%)	125 (19%)	156 (25%)	<0.001
Worry about confidentiality	99 (15%)	195 (22%)	80 (18%)	<0.001	330 (19%)	53 (18%)	0.7	21 (14%)	110 (16%)	137 (20%)	135 (22%)	0.02
Worry medications will not work/hurt me	226 (33%)	273 (31%)	127 (29%)	0.2	564 (32%)	86 (29%)	0.3	37 (24%)	174 (26%)	252 (38%)	208 (34%)	<0.001
Do not understand the studies	26 (4%)	91 (10%)	40 (9%)	<0.001	132 (29%)	29 (10%)	0.2	10 (7%)	78 (12%)	57 (8%)	20 (3%)	<0.001
Do not have time	115 (17%)	126 (14%)	71 (16%)	0.4	275 (16%)	40 (14%)	0.4	18 (12%)	103 (15%)	87 (13%)	120 (19%)	0.01
Do not want to be "guinea pig"	43 (6%)	133 (15%)	43 (10%)	<0.001	211 (12%)	26 (9%)	0.1	18 (12%)	81 (12%)	88 (13%)	53 (9%)	0.07

* Chi-Square Test.

[§] Excluded individuals who responded other race (N=102), mixed race (N=23) or had no response (N=57).

[‡] Excluded individuals who responded other language (N=31) or had no response (N=104).

[‡] Excluded individuals who had no response (N=54).

Table 5

Factors associated with being talked to about participating in an HIV/AIDS clinical trial.

	Unadjusted OR (95% CI)	Adjusted OR (95% CI) ^a
Race		
White	ref	Ref
African-American	0.65 (0.52, 0.81) ^b	0.70 (0.55, 0.89) ^b
Hispanic	0.65 (0.49, 0.85) ^b	0.69 (0.47, 1.02) ^c
Mixed race or other race	0.75 (0.49, 1.14) ^d	0.79 (0.51, 1.22) ^d
Education		
Elementary school	ref	ref
High school	1.18 (0.82, 1.71) ^d	1.18 (0.81, 1.73) ^d
Some college or technical school	1.67 (1.15, 2.43) ^b	1.57 (1.06, 2.33) ^b
College or graduate school	1.89 (1.29, 2.77) ^b	1.68 (1.12, 2.51) ^b
First language		
English	ref	Ref
Spanish	0.86 (0.66, 1.12) ^d	1.08 (0.71, 1.64) ^d
Other	0.63 (0.30, 1.32) ^d	0.61 (0.28, 1.29) ^d
Last use of tobacco		
Never/more than a year ago	ref	Ref
Within past year or past month	0.78 (0.64, 0.94) ^b	0.81 (0.65, 0.98) ^b
Age categories (years)		
Under 25	ref	ref
25–34	0.93 (0.52, 1.67) ^d	0.89 (0.49, 1.61) ^d
35–44	0.72 (0.42, 1.26) ^d	0.67 (0.38, 1.18) ^d
45–54	0.74 (0.43, 1.27) ^d	0.67 (0.39, 1.17) ^d
55	0.89 (0.51, 1.58) ^d	0.78 (0.43, 1.38) ^d
Sex		
Male	ref	ref
Female	1.03 (0.84, 1.27) ^d	1.19 (0.95, 1.49) ^d
Alcohol use (intermittent)		
Never/once a month	ref	
>2–3 times per month	1.21 (0.99 to 1.47) ^c	
Alcohol use (binge)		
Never/once a month	ref	
>2–3 times per month	0.86 (0.67 to 1.10) ^d	

	Unadjusted OR (95% CI)	Adjusted OR (95% CI) ^a
Marijuana use		
Never/more than 1 year ago	ref	
Within past month/year	1.03 (0.83 to 1.28) ^d	
Other drug use (cocaine, heroin, amphetamines)		
Never/more than 1 year ago	ref	
Within past month/year	0.97 (0.72 to 1.29) ^d	

^a Adjusted ORs are from a multivariable model that includes age, education, sex, race, first language and tobacco use. The multivariable (adjusted) analysis does not include alcohol and drug use.

^b p-value<0.05.

^c 0.05<p-value <0.1.

^d p-value 0.1