



## Original article

## Recruiting vulnerable populations to participate in HIV prevention research: findings from the *Together 5000* cohort study



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## ABSTRACT

**Purpose:** The aim of the article was to examine factors associated with completing enrollment milestones in the *Together 5000* cohort of at-risk men ( $n = 8661$ ), transmen ( $n = 53$ ), and transwomen ( $n = 63$ ) who have sex with men.

**Methods:** Between 2017 and 2018, participants completed an online enrollment survey and were offered opportunities to complete an incentivized secondary online survey as well as self-administered at-home HIV testing (OraSure). We explored factors associated with completing each study component.

**Results:** In total, 8777 individuals completed our enrollment survey, 6166 (70.3%) completed the secondary survey, and 5010 returned the at-home HIV test kit that was mailed to them (81.3% of those mailed a kit). In our multivariable models, those who were White, with more years of education, were more likely to complete study components, although the magnitude of these associations was small. For example, 50.9% of those enrolled, 47.9% of those completing the secondary survey, and 46.8% of those completing HIV testing were persons of color—a statistically significant, but meaningfully insignificant decline.

**Conclusions:** These findings highlight the need for researchers to identify barriers that may prevent persons of color and younger individuals from participating in research studies.

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## Introduction

HIV disproportionately affects sexual and gender minorities, including gay and bisexual men (GBM). The Centers for Disease Control and Prevention estimated that 67% of new HIV diagnoses were among GBM in 2016 [1]—GBM represented 83% of all diagnoses among men [2] and 92% of diagnoses among men aged 18–24 years [3]. At this rate, the Centers for Disease Control and

Prevention estimated that one in six men who have sex with men (MSM) will acquire HIV in their lifetime, including one in two Black MSM and one in four Latino MSM [2, 4]. Given the high incidence and burden of disease among MSM, it is vital to understand challenges of preventive services uptake and coverage as well as participation in HIV prevention research to help identify these challenges and their potential solutions.

Internet-based recruitment methods can be efficient for reaching large numbers of geographically diverse individuals in a relatively short period [5–9]. In addition to identifying potential participants for face-to-face assessments, researchers have used the Internet to conduct online assessments [9–12] as well as to deliver fully online interventions [13–18]. The feasibility of

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retaining online samples longitudinally has also been well established [19–21].

In 2008, Apple Inc. launched the first “app” store, allowing smartphone users to install third-party applications that could take full advantage of the phone’s features, namely its mobility [22]. In the years that followed, application developers released geosocial sexual networking applications that can be installed across mobile operating system (e.g., iOS, Android). These types of applications have rapidly been adopted as a means for GBM to meet sex partners and offer important opportunities as recruitment venues for sexual health research studies [6, 9,23–28].

Despite the Internet’s and, more recently, applications’ suitability for researchers to engage large numbers of geographically diverse GBM [12,29–32], public health researchers and practitioners remain concerned about the adequate representation of those most vulnerable to HIV, including younger GBM and persons of color [9, 33]. Historically, persons of color have been harder to recruit, engage, and retain in research studies [34–36], and online-recruited studies have observed greater attrition among men of color during consecutive follow-up assessments [35,37,38]. A 2016 study of over 1000 GBM reported that participants’ ability to complete various study milestones—consent, complete a baseline assessment, return an at-home HIV test via mail—was associated with higher level of education, living in the southern United States, and reporting higher HIV-related risk behaviors [9]. In another study of GBM recruited online that required participants to return an at-home HIV test, findings indicated that compliance was associated with White race, higher education, and higher annual income [33]. There are substantial historical precedents for racial and ethnic minorities to be suspicious of, if not outright avoidant of, scientific research—not the least of which includes the racist injustices committed by the Tuskegee syphilis experiments [39–43].

Taken together, in the present article, we sought to describe factors associated with completing, or not completing, each study milestone in a large, ongoing Internet-based U.S. national cohort study of men, transmen, and transwomen who have sex with men. We explored both behavioral as well as demographic factors. Given the high incidence of HIV among MSM of color and known challenges in engaging them in research, our goal was to enroll approximately 50% persons of color, however, ideally without having to establish quota sampling. By examining factors associated with study procedure attrition, our goal was to inform other HIV prevention researchers seeking to engage those most vulnerable to HIV including the use of novel at-home self-administered HIV testing.

## Methods

### *Cohort recruitment, enrollment, and surveys*

This study uses data collected as part of the *Together 5000* study, a U.S. national, Internet-based cohort study of men, transmen, and transwomen who have sex with men. The overall goal of the study was to identify modifiable individual and structural factors associated with HIV seroconversion and pre-exposure prophylaxis (PrEP) uptake. Enrollment began October 2017 using advertisements on men for men geosocial networking phone applications and concluded in June 2018. Eligibility criteria specified that participants were men, transmen, and transwomen; aged 16–49 years; had at least two male sex partners in the past 3 months; were not currently participating in a HIV vaccine or PrEP clinical trial; were not on PrEP at the time of enrollment; lived in the United States or its territories; self-reported HIV status as HIV negative or unknown; and met at least one of the following additional criteria: diagnosed with syphilis in the past 12 months,

diagnosed with rectal gonorrhea or chlamydia in the past 12 months, shared injection drug use needles in the past 12 months, self-reported more than one receptive condomless anal sex (CAS) act with a man in the past 3 months, self-reported greater than two insertive CAS acts with a man in the past 3 months, took postexposure prophylaxis (PEP) in the past 12 months, and/or self-reported methamphetamine use in the past 3 months. Of note, our recruitment strategies were targeted to reach MSM, but our enrollment criteria did not exclude transmen and transwomen who otherwise met study criteria. Furthermore, our goal was to enroll approximately 50% persons of color, although we did not use quota sampling.

Participants clicking on one of our study advertisements (Fig. 1) were routed from the geosocial applications to a secured informed consent and enrollment survey Webpage that presented questions about demographic characteristics, sexual behavior, and substance use. Eligible participants who consented and completed the enrollment survey were later sent a link (e-mail and text) to complete a secondary survey that collected additional data. Participants completing this secondary survey received a \$15 gift card by e-mail. Participants who completed the second were subsequently mailed an OraSure HIV-1 Oral Specimen Collection Device. Using a self-addressed and stamped envelope, participants mailed oral fluid samples to the study laboratory for analysis. Participants who returned a sample to the laboratory received another \$15 gift card by e-mail.

### *Survey and test kit response rates*

In total, 43,161 individuals began the enrollment survey, and 22,091 (51.2%) completed it. Among those not completing, the vast majority left immediately (i.e., on the informed consent page). Of those who completed the enrollment survey, 8777 unique participants met eligibility criteria and provided contact information for longitudinal follow-up. Of the 8777 participants who enrolled, 6166 (70.3%) completed the secondary survey and were mailed at-home



Fig. 1. Racial differences in percentage of participants passing study milestones.

**Table 1**  
Demographic characteristics by study enrollment or survey milestone, *Together 5000* (T5K) study, 2017–2018, *n* = 8777

Demographic characteristics	Enrolled Completed enrollment survey. Consent for follow-up <i>N</i> = 8777 <i>n</i> (%)	Milestone 1 Completed second survey and mailed an HIV testing kit				Milestone 2 Returned a HIV testing kit to laboratory, valid results			
		Yes <i>N</i> = 6166 <i>n</i> (%)	No <i>N</i> = 2611 <i>n</i> (%)	$\chi^2$	<i>P</i>	Yes <i>N</i> = 5010 <i>n</i> (%)	No <i>N</i> = 1156 <i>n</i> (%)	$\chi^2$	<i>P</i>
Gender	—	—	—	4.37	0.22	—	—	19.76	.0002
Cis man	8554 (97.5)	6016 (97.6)	2538 (97.2)	—	—	4899 (97.8)	1117 (96.6)	—	—
Transwoman	63 (0.7)	41 (0.7)	22 (0.8)	—	—	22 (0.4)	19 (1.6)	—	—
Transman	53 (0.6)	41 (0.7)	12 (0.5)	—	—	37 (0.7)	4 (0.3)	—	—
Nonbinary (male at birth)	107 (1.2)	68 (1.1)	39 (1.5)	—	—	52 (1.0)	16 (1.4)	—	—
Race/ethnicity	—	—	—	115.36	<.0001	—	—	31.11	<.0001
White	4309 (49.1)	3210 (52.1)	1099 (42.1)	—	—	2665 (53.2)	545 (47.2)	—	—
Black or African American	1156 (13.2)	679 (11.0)	477 (18.3)	—	—	507 (10.1)	172 (14.9)	—	—
Latinx	2227 (25.4)	1505 (24.4)	722 (27.7)	—	—	1203 (24.0)	302 (26.1)	—	—
Asian or Pacific Islander	311 (3.5)	224 (3.6)	87 (3.3)	—	—	194 (3.9)	30 (2.6)	—	—
Multiracial/other	774 (8.8)	548 (8.9)	226 (8.7)	—	—	441 (8.8)	107 (9.3)	—	—
Employment status (current)	—	—	—	8.63	.03	—	—	17.75	.0005
Full time	5395 (61.5)	3839 (62.3)	1556 (59.6)	—	—	3181 (63.5)	658 (56.9)	—	—
Part time	1160 (13.2)	804 (13.0)	356 (13.6)	—	—	628 (12.5)	176 (15.2)	—	—
Working or full-time student	1330 (15.2)	930 (15.1)	400 (15.3)	—	—	739 (14.8)	191 (16.3)	—	—
Unemployed/other	892 (10.2)	593 (9.6)	299 (11.5)	—	—	462 (9.2)	131 (11.3)	—	—
Highest level of education	—	—	—	97.46	<.0001	—	—	78.36	<.0001
Less than high school diploma	269 (3.1)	144 (2.3)	125 (4.8)	—	—	106 (2.1)	38 (3.3)	—	—
High school diploma or GED	1391 (15.9)	880 (14.3)	511 (19.6)	—	—	660 (13.2)	220 (19.0)	—	—
Some college or associate's degree	3949 (45.0)	2771 (44.9)	1178 (45.1)	—	—	2195 (43.8)	576 (49.8)	—	—
College graduate or higher	3168 (36.1)	2371 (38.5)	797 (30.5)	—	—	2049 (40.9)	322 (27.9)	—	—
Income	—	—	—	22.66	<.0001	—	—	30.56	<.0001
<\$20,000	3067 (34.9)	2057 (33.4)	1010 (38.7)	—	—	1609 (32.1)	448 (37.8)	—	—
\$20,000–\$49,999	3559 (40.6)	2561 (41.5)	998 (38.2)	—	—	2079 (41.5)	482 (41.7)	—	—
≥\$50,000	2151 (24.5)	1548 (25.1)	603 (23.1)	—	—	1322 (26.4)	226 (19.6)	—	—
Marital status	—	—	—	—	—	—	—	8.97	.003
Yes (marriage license or commitment ceremony)	—	—	—	—	—	665 (13.3)	116 (10.0)	—	—
No	—	—	—	—	—	4345 (86.7)	1040 (90.0)	—	—
Health insurance	—	—	—	—	—	—	—	23.70	<.0001
Yes	—	—	—	—	—	3706 (74.0)	772 (66.8)	—	—
No	—	—	—	—	—	1304 (26.0)	384 (33.2)	—	—
Housing instability	—	—	—	11.60	.001	—	—	23.62	<.0001
Yes, within the last 5 y	1912 (21.8)	1283 (20.8)	629 (24.1)	—	—	982 (19.6)	301 (26.0)	—	—
No or not within the last 5 y	6865 (78.2)	4883 (79.2)	1982 (75.9)	—	—	4028 (80.4)	855 (74.0)	—	—
Sexual identity	—	—	—	29.96	<.0001	—	—	9.60	.01
Gay, queer, homosexual	7314 (83.3)	5224 (84.7)	2090 (80.1)	—	—	4276 (85.4)	948 (82.0)	—	—
Bisexual	1346 (15.3)	860 (14.0)	486 (18.6)	—	—	675 (13.5)	185 (16.0)	—	—
Other (reports sex with men)	117 (1.3)	82 (1.3)	35 (1.3)	—	—	59 (1.2)	23 (2.0)	—	—
Transactional sex in the past 3 mo	—	—	—	0.79	.37	—	—	24.49	<.0001
Yes	7438 (84.7)	927 (15.0)	412 (15.8)	—	—	699 (14.0)	228 (19.7)	—	—
No	1339 (15.3)	5239 (85.0)	2199 (84.2)	—	—	4311 (86.1)	928 (80.3)	—	—
Incarcerated (ever)	—	—	—	—	—	—	—	13.73	.0002
Yes	—	—	—	—	—	688 (13.7)	208 (18.0)	—	—
No	—	—	—	—	—	4322 (86.3)	948 (82.0)	—	—
—	Mean (SD)	Mean (SD)	Mean (SD)	<i>t</i> value	<i>P</i>	Mean (SD)	Mean (SD)	<i>t</i> value	<i>P</i>
Age	30.41 (7.9)	30.54 (7.8)	30.09 (8.0)	−2.49	.01	30.89 (7.9)	29.06 (7.4)	−7.15	<.0001

GED = General Education Development.

HIV kits, and 5010 (81.3%) of those who received kits returned them to the laboratory with samples that yielded valid HIV test results. An additional 56 participants returned kits to the laboratory, but the laboratory was unable to process them (e.g., container opened in transit to the laboratory), and our attempts to resample were unsuccessful.

### Study measures

Variables of interest for the present study included demographic characteristics and sexual health factors related to HIV risk, status, and testing. Demographic characteristics measured in the enrollment survey included age, race/ethnicity, gender identity (i.e., male, transfemale, transmale), sexual identity (e.g., gay, bisexual), employment status, highest level of education, annual income,

experiencing housing instability in the past 5 years, and having performed sex work in the past 3 months. Sexual health variables (also assessed in the enrollment survey) included perceived HIV status at enrollment (negative vs. unknown), HIV testing history, experience with PrEP and PEP, as well as the number of times participants had insertive and/or receptive CAS in the past 3 months. Additional demographic characteristics used for analyses—measured in the secondary survey (thus we lack full data on all participants)—were health insurance status, marital status (including commitment ceremonies), and lifetime incarceration (yes or no).

### Analysis plan

Our objective was to assess sociodemographic and behavioral differences based on whether participants reached each stage of

**Table 2**Description of sexual risk behaviors for the *Together 5000* (T5K) study population by study enrollment or survey milestone, 2017–2018,  $n = 8777$ 

Characteristic	Enrolled	Milestone 1 Completed second survey and mailed an HIV testing kit				Milestone 2 Returned a HIV testing kit to lab, valid results			
	$N = 8777$ $n$ (%)	Yes $N = 6166$ $n$ (%)	No $N = 2611$ $n$ (%)	$\chi^2$	$P$	Yes $N = 5010$ $n$ (%)	No $N = 1156$ $n$ (%)	$\chi^2$	$P$
HIV, PrEP, and PEP status									
HIV status				5.81	.02			41.65	<.0001
Negative	5019 (57.2)	3577 (58.0)	1442 (55.2)	—	—	3004 (60.0)	573 (49.6)	—	—
Unsure	3758 (42.8)	2589 (42.0)	1169 (44.8)	—	—	2006 (40.0)	583 (50.4)	—	—
Last HIV test				8.59	.04			24.49	<.0001
$\leq 6$ mo	3748 (42.7)	2632 (42.7)	1116 (42.7)	—	—	2209 (44.1)	423 (36.6)	—	—
7–12 mo ago	1614 (18.4)	1158 (18.8)	456 (17.5)	—	—	936 (18.7)	222 (19.2)	—	—
A year ago or longer	2292 (26.1)	1626 (26.4)	666 (25.5)	—	—	1278 (25.5)	348 (30.1)	—	—
I have never been tested	1123 (12.8)	750 (12.2)	373 (14.3)	—	—	587 (11.7)	163 (14.1)	—	—
Experience with PrEP				0.05	.82			0.27	.61
I have never taken PrEP/I don't know what PrEP is	7525 (85.7)	5283 (85.7)	2242 (85.9)	—	—	4287 (85.6)	996 (86.2)	—	—
I have taken PrEP, but not currently	1252 (14.3)	883 (14.3)	369 (14.1)	—	—	723 (14.4)	160 (13.8)	—	—
Experience with PEP				0.01	.92			0.002	.96
I have never taken PEP	8226 (93.7)	5780 (93.7)	2446 (93.7)	—	—	4696 (93.7)	1084 (93.8)	—	—
I have taken PEP a year ago or longer	551 (6.3)	386 (6.3)	165 (6.3)	—	—	314 (6.3)	72 (6.2)	—	—
Sexual behaviors	Mean (SD)	Mean (SD)	Mean (SD)	—	—	Mean (SD)	Mean (SD)	—	—
No. of times having receptive CAS*	4.16 (10.7)	4.26 (11.6)	3.94 (8.3)	41.59	<.0001	4.13 (11.7)	4.78 (11.2)	88.66	<.0001
No. of times having insertive CAS*	4.23 (7.8)	4.33 (8.0)	4.00 (7.3)	44.13	<.0001	4.26 (7.7)	4.64 (9.5)	30.92	<.0001

\* Bivariate Poisson regression analyses used to determine differences between mean counts.

study procedure completion. The first group of participants were those who completed the enrollment survey and consented to study follow-up (i.e., Enrolled,  $n = 8777$ ). The next group included those who additionally completed the second survey and were subsequently mailed an at-home HIV testing kit (i.e., Milestone 1,  $n = 6166$ ). The third group of participants were those who returned their HIV test kit to the laboratory with valid testing results (i.e., Milestone 2,  $n = 5010$ ).

Descriptive statistics were used to describe participants enrolled in the study ( $n = 8777$ ), as well as those who reached the additional study milestones. Bivariate tests ( $\chi^2$  and  $t$  tests, as appropriate) were used to assess groups differences (e.g., Enrolled vs. Milestone 1; Milestone 1 vs. Milestone 2) in demographic characteristics and sexual health factors. Bivariate Poisson regression analyses were used to assess group differences for the number of receptive CAS acts and number of insertive CAS acts ( $\chi^2$  values and  $P$  reported). Given our large sample size, and to avoid type 1 errors, we used a statistical significance level of  $\leq .01$ .

Next, we developed two multiple logistic regression models from the results of the bivariate analyses and *a priori* knowledge of known factors associated with HIV risk. To compare participants who enrolled (but *did not* pass Milestone 1,  $n = 2611$ ) versus those who *did* ( $n = 6166$ ), regression analyses included age, gender, race–ethnicity, sexual orientation, employment status, highest level of education, annual income, having experienced housing instability in the past 5 years, transactional sex in the past 3 months, number of times having receptive and insertive CAS, perceived HIV status at enrollment (negative vs. unknown), and HIV testing history. To compare participants who passed Milestone 1 (but *not* Milestone 2,  $n = 1156$ ) versus those who *did* ( $n = 5010$ ), regression analyses included all the variables mentioned previously plus marital status, health insurance status and if participants were ever incarcerated. For all regression analyses,  $\beta$ -estimates, adjusted odds ratios, and 95% confidence intervals are reported. All analyses were completed using SAS 9.4 (SAS Institute, Inc.).

## Results

### Description of participants who were eligible, consented, and enrolled ( $n = 8777$ )

Descriptive statistics for demographic characteristics for all study milestones are presented in Table 1. Among participants enrolled in the study ( $n = 8777$ ), the mean age was 30.4 years ( $SD = 8$ ), and 97.5% identified as cis men. Half (50.9%) of participants identified as persons of color or multiracial/other. Nearly two-thirds (61.5%) reported being fully employed, 45% reported having some college education or an associate's degree, and 40.6% reported an annual income between \$20,000 and \$49,999. Most participants were not in a same-sex marriage (87.5%), and most (83.3%) identified as gay, queer, or homosexual. A quarter (27.5%) reported that they did not have or were unsure if they had health insurance, and 21.8% had experienced housing instability in the past 5 years. Finally, 15.3% reported engaging in transactional sex in the past 3 months, and 14.8% reported ever being incarcerated.

Regarding sexual and HIV-related health behaviors (Table 2), the average number of receptive CAS acts in the past 3 months was 4 ( $SD = 11$ , interquartile range: 1–4) and the average number of insertive CAS occurrences was also 4 ( $SD = 8$ , interquartile range: 1–5). Four in 10 participants (42.8%) said they were unsure of their HIV status at the time of enrollment, and one in eight (12.8%) had never tested for HIV. In total, 14% of participants reported prior—but not current—PrEP use. Most (94%) of our participants had never take PEP.

### Bivariate comparisons of Milestone 1 completers (the secondary survey, $n = 6166$ ) and noncompleters ( $n = 2611$ )

When compared with men who did *not* complete Milestone 1, those who completed the secondary survey were likely to be White (42.1% vs. 52.1%), employed full-time (59.6% vs. 62.3%), earn a higher income, have more education, and identify as gay (80.1% vs.

**Table 3**  
Associations of demographic characteristics with passing Milestone 1 and Milestone 2, *Together 5000* (T5K) study, 2017–2018, *n* = 8777

	Passed milestone 1 (yes vs. no)					Passed milestone 2 (yes vs. no)				
	Completed secondary survey and mailed an HIV testing kit					Returned a HIV testing kit to laboratory, valid results				
	Estimate (B)	Wald 95% confidence limits	aOR	95% CI	<i>P</i>	Estimate (B)	Wald 95% confidence limits	aOR	95% CI	<i>P</i>
Age*	−0.02	−0.05 0.02	0.98	0.95–1.02	.3774	0.15	0.09 0.20	1.16	1.10–1.22	<.0001
Gender										
Cis man	Ref					Ref				
Transwoman	−0.10	−0.66 0.47	0.91	0.51–1.60	.7320	−1.11	−1.79 −0.43	0.33	0.17–0.65	.0014
Trans man	0.40	−0.26 1.05	1.49	0.77–2.87	.2333	0.90	−0.15 1.95	2.46	0.86–7.05	.0928
Nonbinary (male at birth)	−0.28	−0.70 0.15	0.76	0.50–1.16	.1993	−0.12	−0.71 0.47	0.89	0.49–1.59	.6860
Race/ethnicity										
White	Ref					Ref				
Black or African American	−0.65	−0.80 −0.51	0.52	0.45–0.60	<.0001	−0.34	−0.55 −0.13	0.71	0.58–0.88	.0015
Latino	−0.32	−0.44 −0.21	0.72	0.64–0.81	<.0001	−0.10	−0.27 0.07	0.90	0.77–1.07	.2365
Asian or Pacific Islander	−0.22	−0.49 0.04	0.80	0.61–1.04	.0983	0.09	−0.32 0.50	1.10	0.73–1.65	.6539
Multiracial/other	−0.13	−0.30 0.05	0.88	0.74–1.05	.1559	−0.02	−0.27 0.22	0.98	0.77–1.24	.8408
Employment status (current)										
Full time	Ref					Ref				
Part time	0.07	−0.08 0.23	1.08	0.92–1.26	.3459	−0.12	−0.33 0.09	0.89	0.72–1.10	.2697
Working or full-time student	0.07	−0.09 0.24	1.08	0.92–1.27	.3646	0.06	−0.16 0.28	1.06	0.85–1.33	.6051
Unemployed/other	−0.03	−0.21 0.15	0.97	0.81–1.16	.7442	−0.14	−0.39 0.10	0.87	0.68–1.11	.2502
Highest level of education										
Less than high school diploma	−0.41	−0.68 −0.14	0.66	0.50–0.87	.0029	−0.01	−0.42 0.41	0.99	0.65–1.51	.9757
High school diploma or GED	Ref					Ref				
Some college or associate's degree	0.27	0.14 0.41	1.31	1.15–1.51	<.0001	0.14	−0.05 0.33	1.15	0.95–1.39	.1514
College graduate or higher	0.50	0.34 0.65	1.64	1.41–1.91	<.0001	0.48	0.26 0.69	1.61	1.29–2.00	<.0001
Income										
<\$20,000	0.06	−0.10 0.23	1.06	0.90–1.25	.45	0.22	−0.02 0.45	1.24	0.98–1.57	.0745
\$20,000–\$49,999	0.17	0.04 0.30	1.19	1.04–1.36	.01	0.10	−0.09 0.29	1.11	0.91–1.34	.2958
≥\$50,000	Ref					Ref				
Housing instability										
Yes, within the last 5 y	−0.10	−0.23 0.02	0.90	0.80–1.02	.0964	−0.10	−0.27 0.07	0.90	0.76–1.07	.2504
No or not within the last 5 y	Ref					Ref				
Marital status										
Yes (marriage license or commitment ceremony)	—					—	—	—	—	—
No	—					−0.15	−0.37 0.07	0.86	0.69–1.08	.19
Health insurance										
Yes	—					—	—	—	—	—
No	—					−0.12	−0.27 0.04	0.89	0.76–1.04	.15
Sexual orientation										
Gay, queer, homosexual	Ref					Ref				
Bisexual	−0.24	−0.37 −0.11	0.78	0.69–0.89	.0003	−0.15	−0.33 0.04	0.86	0.72–1.04	.12
Other	0.18	−0.25 0.61	1.20	0.78–1.85	.4173	−0.15	−0.69 0.40	0.86	0.50–1.49	.6005
Transactional sex in the past 3 months										
Yes	0.08	−0.06 0.22	1.09	0.95–1.25	.24	−0.08	−0.27 0.10	0.92	0.76–1.11	.3788
No	Ref					Ref				
Incarceration										
Yes	—					−0.18	−0.38 0.01	0.83	0.69–1.01	.0606
No	—					Ref				
No. of times having receptive CAS <3 mo	0.00	0.00 0.01	1.00	1.00–1.01	.5604	0.00	−0.01 0.00	1.00	0.99–1.00	.3872
No. of times having insertive CAS <3 mo	0.01	0.00 0.01	1.01	1.00–1.01	.1182	0.00	−0.01 0.00	1.00	0.99–1.00	.3654
Perceived HIV status at enrollment										
Negative	Ref					Ref				
Unsure	−0.07	−0.18 0.05	0.94	0.83–1.05	.2568	−0.25	−0.41 −0.09	0.78	0.66–0.92	.0025
Last HIV test										
≤6 mo	Ref					Ref				
7–12 mo ago	0.11	−0.03 0.24	1.11	0.97–1.28	.1225	−0.14	−0.33 0.06	0.87	0.72–1.06	.1645
A year ago or longer	0.10	−0.03 0.23	1.11	0.97–1.26	.1378	−0.14	−0.45 −0.08	0.77	0.64–0.92	.0053

**Table 3** (continued)

	Passed milestone 1 (yes vs. no)					Passed milestone 2 (yes vs. no)				
	Completed secondary survey and mailed an HIV testing kit					Returned a HIV testing kit to laboratory, valid results				
	Estimate (B)	Wald 95% confidence limits	aOR	95% CI	P	Estimate (B)	Wald 95% confidence limits	aOR	95% CI	P
I have never been tested	0.03	−0.14 0.21	1.04	0.87–1.23	.6920	−0.26 0.06	−0.18 0.30	1.06	0.83–1.35	.6366

aOR = adjusted odds ratio; CI = confidence interval; GED = general education development.

\* Age scaled to 5-y increase.

84.7%). Milestone 1 completers reported a greater mean number of recent CAS acts (insertive and receptive) and were less likely to have experienced recent housing instability.

#### *Bivariate comparisons of Milestone 2 completers (HIV testing, n = 5010) and noncompleters (n = 1156)*

Among those mailed an HIV test kit ( $n = 6166$ ), we next compared those who returned a valid sample to the laboratory ( $n = 5010$ ; i.e., completed Milestone 2) versus those who did not return an HIV test kit ( $n = 1156$ ). Compared with those who did not return an HIV test kit, those who did were more likely to be older (29.1 vs. 30.9 years) and White (47.2% vs. 53.2%), employed full-time (56.9% vs. 63.5%), earn a higher income, have more education, identify as gay (82.0% vs. 85.4%), have health insurance (66.8% vs. 74.0%), be married (10.0% vs. 13.3%), and cis man (96.6% vs. 97.8%). Compared with those who returned an HIV test kit, those who did not were significantly more likely to have experienced unstable housing recently, ever been incarcerated, and appeared to have been at greater risk for HIV—they reported a greater number of recent CAS acts, were more likely to say they were unsure of their HIV status at enrollment, and more likely to have *never* been tested for HIV.

#### *Multivariable factors associated with completing study milestones*

In multivariable logistic regression, factors independently associated with Milestone 1 (i.e., completing the secondary survey) versus not were being older and having more education. Compared with White men, Black–African American and Latino participants were less likely to complete the secondary survey. Participants identifying as bisexual were also less likely to complete the secondary survey (Table 3).

Regression analyses for factors associated with completing Milestone 2 (i.e., returning a valid HIV test sample vs. not) indicated similar associations found in Milestone 1 analyses for age and level of education. Compared with White men, Black–African American participants were less likely to return an HIV test kit. Compared with cis men, transwomen were significantly less likely to return an HIV test kit. Those failing to return a kit were also more likely to say they did not know their HIV status and to have last tested for HIV more than a year ago. In both models, although we identified statistical significance in these associations, the magnitude of these associations was small. These are discussed further in the next section.

## **Discussion**

We explored factors associated with completing stages of study enrollment procedures in a large, diverse U.S. national cohort of individuals at risk for HIV. In our multivariable models, White, better-educated participants were more likely to complete study components—as has been observed by others [9, 15, 35, 37, 38, 44]. These findings highlight the ongoing need for researchers to

identify barriers that prevent persons of color, particularly Black men, from both enrolling and being retained in research as well as use tailored methods for enhancing retention [19–21].

That being said, and in spite of greater attrition we observed among persons of color, we highlight that our goal during recruitment was to enroll a sample that was approximately 50% persons of color and to do so *without* setting quotas. Of note, our advertisements featured images that included men of color, and we closely approximated this goal—50.9% were persons of color at enrollment, 47.9% of participants completing our secondary survey were persons of color, and 46.8% of those who returned an HIV test kit were persons of color (Fig. 2). Furthermore, in multivariable models and compared with White participants, Latinos, Asians, and multiracial or “other” participants were not less likely to return an HIV test kit—in this model, only Black participants differed from White participants. Thus, although some racial differences in attrition were observed, these appear to have been lower in our study compared with others. It is possible the differences between our study and others were a factor of differences in enrollment criteria, study procedures, or incentives. Furthermore, our study featured men of color in the advertisements and that might have improved response rates.

A second notable finding from our multivariable models was that, although perceived HIV status at enrollment (HIV negative vs. unknown) and prior HIV testing history were *not* associated with completing our secondary survey (i.e., Milestone 1), *both* were associated with failing to return an HIV test kit (i.e., Milestone 2). Those who were unsure of their HIV status or who had not tested recently are perhaps the most critical to engage in HIV testing, and at-home self-administered HIV testing could be an effective way to reach such individuals. Indeed, we enrolled 3415 individuals who had *not* been tested for HIV in the last year, 1857 of whom completed HIV testing. Taking an HIV test can be anxiety provoking, and additional support in the form of telephone- or text-based HIV pretest counseling might be appropriate to enhance uptake, particularly among those most at risk.

We also wish to note that the *type* of test used could also impact whether someone is willing to complete it at home. In our study, we used the OraSure HIV-1 Oral Specimen Collection Device, which must be sent to a laboratory for analysis. In 2012, the Food and Drug Administration approved a rapid at-home HIV test kit that can produce results in 20 minutes, and this might have been more acceptable for some participants [45, 46]. We opted not to use this test, given the added challenges that accurately capturing those results from participants would have posed to study integrity. Another study having used this kit asked participants to report their results via a digital photo of the test paddle [9], but there is some risk in underestimating the number of HIV-positive cases, given that these participants may be reluctant to send a photo of those results. Plus, there is a narrow window of time in which results can be interpreted (between 20 and 40 minutes after testing).

A third important finding from this study was the number of factors observed to be significant at the bivariate level that were not

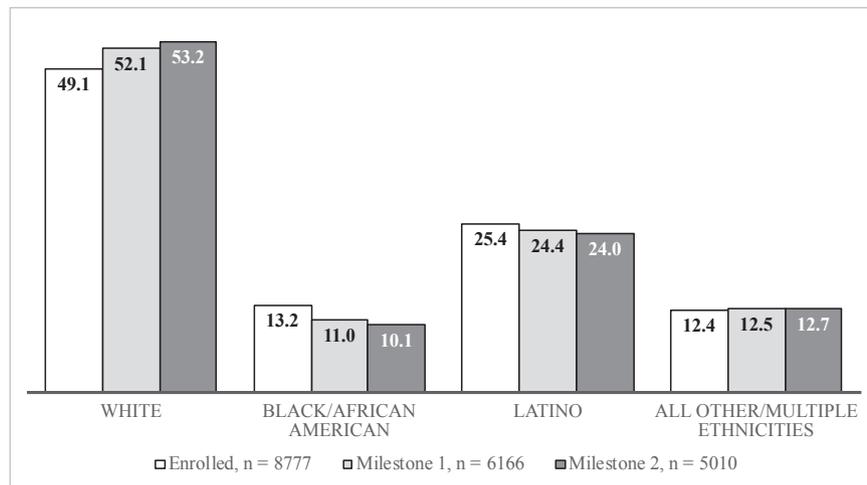


Fig. 2. Racial/ethnic differences in the percentage of participants passing study milestones.

significant at the multivariate level. These were factors generally considered as variables that put individuals at risk for HIV (e.g., number of CAS acts, transactional sex, incarceration, lack of health insurance, housing instability). Although it is not surprising that some variables, which were significant at the bivariate level, were no longer significant in multivariable analyses, our findings highlight the importance of using multivariable models to identify factors that *uniquely* contribute to study attrition—controlling for potential confounding factors is crucial to obtain an unbiased effect estimate. We also note that there was insufficient evidence to suggest this was due to multicollinearity (data not shown). In the present study, we did not examine HIV risk or infection as an outcome, rather whether these factors would be associated with completing an online survey and completing at-home HIV testing. The fact that they were not significant suggests that, at least in our study, known factors that increase the risk for HIV infection were not barriers to engaging individuals in an online survey nor HIV testing.

Our findings should be understood in light of their limitations. Although online studies can increase geographic reach and accessibility, these studies can also increase the potential for fraudulent participants [23, 47–50]. In our study, the only way participants could have learned about the study was via an advertisement sent to them on a sexual networking application, and advertisements were geo-fenced to users within the United States and its territories. Using cookies, our enrollment survey blocked multiple submissions. Next, much of our data were self-reported, which is subject to recall bias and social desirability. Third, although consistent with what other researchers have documented, a large number of participants quit the enrollment survey immediately. Because we lack data on these individuals, we are unable to characterize how they may differ from those who completed the enrollment survey. Fourth, biological samples (HIV testing) improves the rigor of our design (over self-report), but we also acknowledge that we have no way to verify the samples obtained actually belonged to the participants. Of note, however, participants' results had no bearing on whether they would receive the incentive for testing nor whether they would be eligible to remain in the cohort longitudinally. Fifth, although our sample size is large and geographically diverse, it does not generalize to all individuals at risk for HIV and because participants were offered an opportunity for a mailed at-home HIV test kit, those who were homeless or experiencing serious housing instability may have opted not to respond to our advertisements. Sixth, the applications we advertised on were unable to provide us with consistent data on impressions delivered and click-through-rates.

## Conclusion

We expected that not all participants enrolled in the study would complete all study components and highlight that our rates of secondary survey return (70.3%), and HIV test kit return (81.3%) was similar to that observed by other researchers [9, 36]. That being said, rates of attrition in our study varied in ways that have been observed by others and in ways that are counterintuitive to HIV prevention efforts, that is, those individuals who are most vulnerable to acquiring the virus were the most likely to be lost to follow-up. Our findings highlight the need for researchers to examine factors associated with attrition as well as institute study procedures that will minimize it. These could include efforts to enhance trust or prepublicity of the researchers themselves, the use of peers to “coach” participants through enrollment steps, or alternate incentive structures that encourage retention (e.g., a “bonus” incentive if a particular research step is completed within a given period of time). Finally, we highlight that online methods of outreach and research are not meant to supplant traditional face-to-face methods, as each has its unique capabilities and sets of limitations.

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