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HIV Testing Preferences and Characteristics of Those Who Have Never Tested for HIV in the United States

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Abstract

Background: The initial phase of the federal Ending the HIV Epidemic in the U.S. (EHE) initiative prioritized efforts in 57 geographic areas. The US Centers for Disease Control and Prevention recommends persons aged 13 to 64 years be tested for HIV at least once as part of routine health care; however, it is unclear how effectively these testing recommendations have been implemented in EHE priority areas.

Methods: In 2021 to 2022, we analyzed data from a Web-based, nationally representative survey of adults fielded in 2021. HIV testing preferences were compared by testing history, demographic characteristics, behaviors, and geography.

Results: An estimated 72.5% of US adults had never tested for HIV. Never testing was most prevalent among those aged 18 to 29 or those 50 years or older, non-Hispanic White persons, and those living in the Midwest. Among persons living in EHE priority areas and persons reporting at least one behavior that increases risk of HIV transmission, 69.1% and 48.0%, respectively, had never tested for HIV. The top 3 HIV testing preferences among never testers were as follows: testing for HIV during a routine health care visit (41.2%), testing at an urgent care or walk-in clinic (9.6%), and self-testing (8.1%).

Conclusions: Most adults had not been tested for HIV, confirming that US Centers for Disease Control and Prevention recommendations are not being fully implemented, even in EHE priority areas. Moreover, most adults who never tested preferred testing in clinical settings, highlighting missed opportunities. As the EHE initiative continues to advance, it is critical to leverage preferred HIV testing modalities, such as routine testing in clinical settings or HIV self-testing.

In 2019, more than 1.1 million people 13 years or older were living with HIV, and more than 36,000 received an HIV diagnosis in the United States.[1] An estimated 1 in 7 people with

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HIV had an undiagnosed infection.[2] Awareness of HIV infection is critical to timely linkage to care for sustained viral suppression and decreased transmission. The Centers for Disease Control and Prevention (CDC) recommends persons aged 13 to 64 years be tested for HIV at least once in their lifetime as part of routine health care.[3] The National HIV Strategic Plan and the Ending the HIV Epidemic in the U.S. (EHE) initiative aim to reduce the number of new HIV infections by 90% by 2030.[4,5] Accelerating the identification of undiagnosed infections through a range of testing interventions such as clinic-based and pharmacy-based testing[6] and the dissemination of HIV self-tests[7] may facilitate access to testing among those who never previously tested. Increased uptake of HIV testing is a public health priority, and current data on HIV testing trends are critical for continued monitoring and improved programmatic implementation.

Using a national survey, we assessed (1) characteristics of persons who had ever and never tested for HIV and (2) testing preferences of persons never tested overall and by age, race/ethnicity, and residence in EHE priority areas.

METHODS

Sample

Data from the Porter Novelli SpringStyles survey, conducted from March 23, 2021, to April 13, 2021, via an online panel representative of the noninstitutionalized adult US population,[8] were analyzed in 2021 to 2022. Panel members were randomly recruited by mail using probability-based sampling to reach participants regardless of whether they had landline telephones or Internet access.[9] The survey was sent to 10,919 panelists, of which 6455 completed the survey (response rate, 59.1%) and 6072 responded to the question about HIV testing history. The CDC obtained a license from Porter Novelli to access Styles data sets; because this study reports a secondary analysis of deidentified data, institutional review board approval was not required.

Measures

Participants were asked about demographic characteristics, testing history, and behaviors that increase the risk of HIV transmission in the past 12 months. Participants who reported any of the following in the past 12 months were classified as having engaged in a behavior that increases the risk of HIV transmission: (1) injected drugs other than those prescribed, (2) treated for an sexually transmitted disease (STD), (3) exchanged sex for money or drugs, (4) had anal sex without a condom, or (5) had 4 or more sex partners. Although having 2 or more partners may also increase the risk of HIV transmission, this measure used a cutoff of 4 or more partners to align with similar measures used in other national surveys such as the Behavioral Risk Factor Surveillance System.[10]

Participants were asked to select up to 3 most preferred options from a list of 10 testing modalities or indicate that they did not want to test. Participants were classified as living in an EHE priority area if their zip code at least partially matched 1 of 57 EHE priority areas.[11]

Analysis

Weighted proportions with 95% confidence intervals (CIs) were calculated for ever testing and never testing overall and by demographic characteristics, behaviors that increase risk of HIV transmission, and testing preferences. Rao-Scott χ^2 tests compared those who ever tested and never tested for HIV by key characteristics. Among those who never tested, testing preferences by age group (18–39 and ≥40 years) and racial/ethnic group were analyzed using weighted proportions and 95% CIs. Analyses were conducted using SAS 9.4 (SAS Institute, Cary, NC).

RESULTS

An estimated 72.5% (95% CI, 71.2%–73.9%) of US adults never tested for HIV (Table 1). Nearly 80% of adults aged 18 to 29 years and those 50 years or older never tested for HIV. A lower proportion of Black/African American (53.5%; 95% CI, 48.3%–58.7%) and Hispanic adults (69.3%; 95% CI, 65.3%–73.3%) never tested compared with White adults (76.0%; 95% CI, 74.5%–77.5%). Adults in the Midwest had the highest proportion of never testing (77.3%; 95% CI, 74.7%–79.9%) by region; the lowest proportion of never testing was in the Northeast (69.0%; 95% CI, 65.7%–72.4%). A lower proportion of adults residing in EHE priority areas (69.1%; 95% CI, 66.6%–71.5%) never tested compared with those not residing in EHE priority areas (74.5%; 95% CI, 72.9%–76.1%). Of adults who engaged in past-year behaviors that increase the risk of HIV transmission, 48.0% (95% CI, 41.6%–54.4%) never tested for HIV.

Among those who never tested for HIV (Table 2), the 5 most preferred HIV testing modalities included the following: (1) “get tested at a routine visit with my regular health care provider” (41.2%; 95% CI, 39.5%–43.0%), (2) “get tested at an urgent care or walk-in clinic” (9.6%; 95% CI, 8.4%–10.7%), (3) “order an HIV test online and test myself at home” (8.1%; 95% CI, 7.1%–9.1%), (4) “pick up an HIV test at a pharmacy or other location and test myself at home” (7.2%; 95% CI, 6.3%–8.1%), and (5) “get tested at an STD clinic” (6.2%; 95% CI, 5.1%–7.2%). Nearly half (43.9%) of those who never tested did not want to be tested for HIV.

Among never testers 40 years or older and those who were non-Hispanic White or “other” race/ethnicity (Table 3), the 3 most frequently cited preferences were the same as the overall sample. Younger adults (18–39 years) and Black or Hispanic adults preferred testing at an STD clinic as their third preference compared with fifth preference overall.

Among those who never tested, there were few differences in preference order between those who lived in EHE priority areas compared with those not living in EHE priority areas (Fig. 1). Testing in clinical settings (routine visit with regular health care provider or testing at an urgent care or walk in clinic) and HIV self-testing (ordering self-test online or picking it up from a pharmacy) ranked as the top preferences among never testers independently of where they lived.

DISCUSSION

Almost three-quarters of US adults have never tested for HIV, confirming that CDC recommendations are not being fully implemented, even in EHE priority areas. Although never testing was less prevalent among those living in EHE priority areas (69%) compared with those not living in EHE priority areas (75%), the proportion of never testers nationwide was high. However, more than half (56%) of those who never tested indicated preferred testing modalities, suggesting the potential to reach these individuals with tailored testing services. Testing in clinical settings ranked as a top preference, indicating missed opportunities and highlighting the need to continue promoting routine HIV testing in clinical settings as a key strategy to achieve national goals.[4]

Forty-four percent of never testers did not want to be tested for HIV. As the EHE initiative expands from priority areas to the whole country, there should be an increased focus on reaching those who have never tested[12] and those never tested who refuse testing. Understanding reasons for refusals among never testers and how to increase HIV testing acceptance is needed to achieve EHE goals. This survey did not ask about reasons for not wanting to test for HIV. Other studies have identified HIV-related stigma[13] and low perceived risk for HIV infection[14] as common factors that may reduce willingness to test for HIV.

HIV self-testing was also a top preference among those never tested, including acquiring HIV self-tests online or through a pharmacy to test at home. This preference for self-testing might have been influenced by the normalization of self-testing during the COVID-19 pandemic. HIV self-testing programs continue to be promoted and implemented to ensure the continuation of HIV testing beyond the COVID-19 pandemic.[7,15]

LIMITATIONS

This analysis has limitations. First, data were obtained from opt-in survey panel members who may not represent the overall population; however, data were weighted to match 2019 Census data on several factors. Second, it was not possible to examine preferences of participants who tested previously but not recently because testing frequency measures were not collected. Third, the survey did not collect information about participants' access to or utilization of health care, which could have influenced their testing preferences or willingness to test. Lack of access to health care likely contributes to low HIV testing uptake.

CONCLUSIONS

As the EHE initiative expands to the entire country, it is critical to leverage different testing modalities, such as routine testing in clinical settings or self-testing, particularly among those who have never tested for HIV. Understanding preferred modalities for HIV testing, particularly among those who never tested and how to encourage those who do not want to test, is essential to reach these populations and achieve EHE goals.

REFERENCES

1. Centers for Disease Control and Prevention. HIV Surveillance Report. 2019; 32. Available at: http://www.cdc.gov/hiv/library/reports/hiv-surveillance.html. Published May 2021. Accessed July 20, 2022.
2. Centers for Disease Control and Prevention. Estimated HIV incidence and prevalence in the United States, 2015–2019. HIV Surveill Suppl Rep 2021; 26. Available at: http://www.cdc.gov/hiv/library/reports/hiv-surveillance.html. Published May 2021. Accessed July 20, 2022.
3. Branson BM, Handsfield HH, Lampe MA, et al. Revised recommendations for HIV testing of adults, adolescents, and pregnant women in health-care settings. MMWR Recomm Rep 2006; 55(RR-14):1–17.
4. The White House. National HIV/AIDS Strategy for the United States 2022–2025. Washington, DC: The White House, 2021. Available at: https://www.whitehouse.gov/wp-content/uploads/2021/11/National-HIV-AIDS-Strategy.pdf. Accessed May 24, 2022.
5. Fauci AS, Redfield RR, Sigounas G, et al. Ending the HIV Epidemic: A plan for the United States. JAMA 2019; 321:844–845. [PubMed: 30730529]
6. Collins B, Bronson H, Elamin F, et al. The “No Wrong Door” approach to HIV testing: Results from a statewide retail pharmacy-based HIV testing program in Virginia, 2014–2016. Public Health Rep 2018; 133(suppl 2):34S–42S. [PubMed: 30457955]
7. Hecht J, Sanchez T, Sullivan PS, et al. Increasing access to HIV testing through direct-to-consumer HIV self-test distribution—United States, March 31, 2020–March 30, 2021. MMWR Morb Mortal Wkly Rep 2021; 70:1322–1325. [PubMed: 34555001]
8. Porter Novelli. ConsumerStyles & YouthStyles. 2021. Available at: http://styles.porternovelli.com/consumer-youthstyles/. Accessed January 12, 2022.
9. Yeager DS, Krosnick JA, Chang LC, et al. Comparing the accuracy of RDD telephone surveys and Internet surveys conducted with probability and non-probability samples. Public Opin Q 2011; 75:709–747.
10. BRFSS Questionnaires. Available at: https://www.cdc.gov/brfss/questionnaires/index.htm. Accessed November 8, 2022.
11. Centers for Disease Control and Prevention. Ending the HIV Epidemic in the U.S. (EHE). Available at: https://www.cdc.gov/endhiv/jurisdictions.html. Accessed March 16, 2022.
12. Pitasi MA, Delaney KP, Brooks JT, et al. HIV testing in 50 local jurisdictions accounting for the majority of new HIV diagnoses and seven states with disproportionate occurrence of HIV in rural areas, 2016–2017. MMWR Morb Mortal Wkly Rep 2019; 68:561–567.
13. Carey JW, Courtenay-Quirk C, Carnes N, et al. HIV testing program activities and challenges in four U.S. urban areas. AIDS Educ Prev 2022; 34:99–115. [PubMed: 35438537]
14. Gebrezgi MT, Mauck DE, Sheehan DM, et al. Acceptance of opt-out HIV screening in outpatient settings in the United States: A systematic review and meta-analysis. Public Health Rep 2019; 134:484–492. [PubMed: 31365316]
15. Chavez PR, Emerson B, Lilo E, et al. CDC’s direct-to-consumer distribution of 100,000 HIV self-tests. Oral Presentation. 2022 Advancing HIV, STI and Viral Hepatitis Testing Conference March 2022. Available at: https://hivtestingconference.org/wp-content/uploads/2022/04/Chavz_B3Session3.pdf. Accessed July 20, 2022.

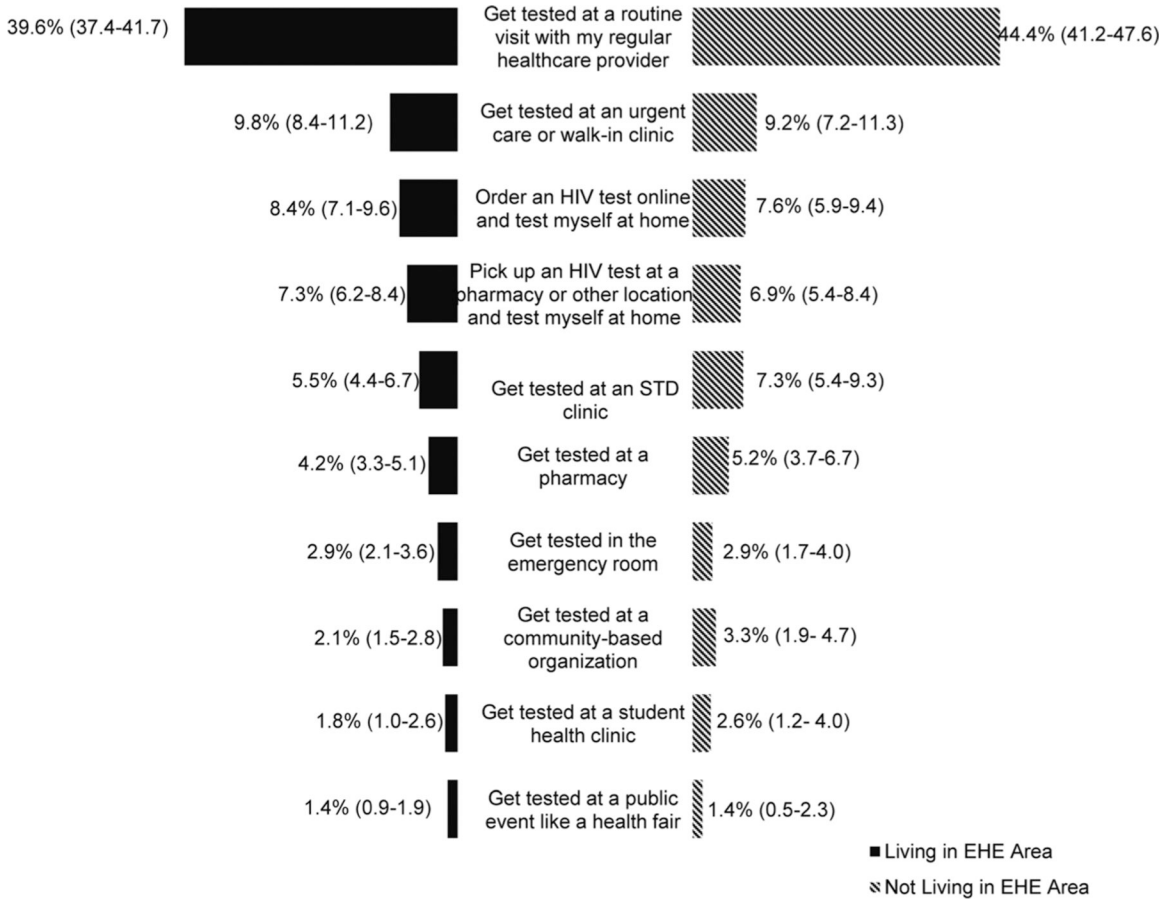

Figure 1.

Testing preferences of never testers living in EHE areas and those not living in EHE Areas, United States, 2021. Footnote: Participants living in zip codes or states that matched jurisdictions identified as focus areas for phase 1 of the EHE initiative were categorized as living in an EHE area, and remaining participants were categorized as not living in an EHE area.

TABLE 1.

Prevalence of Key Characteristics by HIV Testing History in the United States, 2021

		Ever Tested (n = 1738)	Never Tested (n = 4334)	
Demographic and Behavioral Characteristics	**Unweighted Frequency (N)**	**Weighted Percent (95% CI)**	**Weighted Percent (95% CI)**	***P***
Total	6072	27.5 (26.1–28.8)	72.5 (71.2–73.9)	**<0.0001**
Age, y				
18–29	519	20.3 (16.6–24.0)	79.7 (76.0–83.4)	**<0.0001**
30–39	943	40.0 (36.3–43.8)	59.9 (56.2–63.8)	
40–49	1405	39.7 (36.4–43.0)	60.3 (57.0–63.6)	
≥50	3205	21.9 (20.3–23.5)	78.1 (76.5–79.7)	
Sex				
Male	2861	26.3 (24.3–28.2)	73.7 (71.8–75.7)	0.0902
Female	3211	28.6 (26.7–30.6)	71.4 (69.5–73.3)	
Race/Ethnicity				
Non-Hispanic White	4455	24.0 (22.5–25.5)	76.0 (74.5–77.5)	**<0.0001**
Non-Hispanic African American/Black	472	46.5 (41.3–51.7)	53.5 (48.3–58.7)	
Non-Hispanic other	454	22.2 (17.6–26.9)	77.8 (73.1–82.4)	
Hispanic	691	30.7 (26.7–34.7)	69.3 (65.3–73.3)	
Education				
Less than high school	279	31.2 (25.3–37.2)	68.8 (62.8–74.7)	**0.0003**
High school graduate	1301	22.2 (19.7–24.8)	77.8 (75.2–80.3)	
Some college	1856	29.7 (27.2–32.1)	70.4 (67.9–72.8)	
Bachelor’s degree or higher	2636	28.7 (26.6–30.7)	71.4 (69.3–73.4)	
Annual income				
<$25,000	537	35.0 (30.1–39.8)	65.1 (60.2–69.9)	**0.0004**
$25,000–$49,999	895	25.4 (22.0–28.7)	74.6 (71.3–78.0)	
$50,000–$99,999	1994	25.0 (22.6–27.3)	75.1 (72.7–77.4)	
≥$100,000	2646	28.2 (26.1–30.2)	71.8 (69.8–73.9)	
Employment				
Unemployed	2123	21.9 (19.8–24.0)	78.1 (76.0–80.2)	**<0.0001**
Employed	3949	31.1 (29.3–32.9)	68.9 (67.1–70.7)	

Demographic and Behavioral Characteristics	Unweighted Frequency (N)	Ever Tested (n = 1738) Weighted Percent (95% CI)	Never Tested (n = 4334) Weighted Percent (95% CI)	*P*
Region of residence				
Northeast	1058	31.0 (27.6–34.3)	69.0 (65.7–72.4)	**0.0018**
Midwest	1443	22.7 (20.1–25.3)	77.3 (74.7–79.9)	
South	2135	28.0 (25.7–30.3)	72.0 (69.7–74.3)	
West	1436	28.3 (25.4–31.1)	71.8 (68.9–74.6)	
Behaviors that increase risk for HIV Infection*				
No	5694	25.9 (24.5–27.2)	74.2 (72.7–75.5)	**<0.0001**
Yes	378	52.0 (45.6–58.4)	48.0 (41.6–54.4)	
Living in EHE priority area†				
No	4071	25.5 (23.9–27.1)	74.5 (72.9–76.1)	**0.0002**
Yes	2001	30.9 (28.5–33.4)	69.1 (66.6–71.5)	

Boldface indicates statistical significance ($P < 0.05$).

*Participants who reported any of the following behaviors that increase the risk of HIV transmission in the past 12 months were coded as yes: (1) “injected drugs other than those prescribed,” (2) “been treated for an STD,” (3) “exchanged sex for money or drugs,” (4) “had anal sex without a condom,” or (5) “had four or more sex partners.”

†Participants living in zip codes or states that matched jurisdictions identified as focus areas for phase 1 of the EHE initiative were categorized as living in an EHE priority area; remaining participants were categorized as not living in an EHE priority area.

EHE indicates Ending the HIV Epidemic in the U.S. federal initiative.

TABLE 2.

HIV Testing Preferences Among Those Ever and Never Tested in the United States, 2021

Testing Preferences*	Ever Tested (n = 1738)	Never Tested (n = 4334)
	Weighted Column Percent (95%CI)	Weighted Column Percent (95%CI)
I don't want to be tested for HIV	9.1 (7.4–10.8)	43.9 (42.1–45.7)
Get tested at a routine visit with my regular health care provider	69.6 (66.8–72.4)	41.2 (39.5–43.0)
Get tested at an urgent care or walk-in clinic	14.0 (12.0–16.0)	9.6 (8.4–10.7)
Order an HIV test online and test myself at home	11.1 (9.3–12.9)	8.1 (7.1–9.1)
Pick up an HIV test at a pharmacy or other location and test myself at home	9.1 (7.5–10.8)	7.2 (6.3–8.1)
Get tested at an STD clinic	14.0 (11.8–16.2)	6.2 (5.1–7.2)
Get tested at a pharmacy	5.4 (4.1–6.7)	4.5 (3.8–5.3)
Get tested at a community-based organization	7.2 (5.8–8.7)	2.6 (1.9–3.2)
Get tested in the emergency room	4.3 (3.1–5.5)	2.9 (2.2–3.5)
Get tested at a public event like a health fair	3.4 (2.3–4.6)	1.4 (1.0–1.9)
Get tested at a student health clinic	3.1 (1.9–4.3)	2.1 (1.4–2.8)

*Participants could select up to 3 HIV testing preferences, including the option to not get tested. Selecting "I don't want to be tested for HIV" (n = 1957) precluded them from selecting other testing preferences. Otherwise, preference selection was not mutually exclusive. Percentages add up to more than 100%.

TABLE 3.

HIV Testing Preferences Among Those Never Tested by Age and Race/Ethnicity in the United States, 2021

	Overall	18–39 y	≥40 y	White, Non-Hispanic	Black, Non-Hispanic	Other, Non-Hispanic	Hispanic
Testing Preferences*	**Unweighted Frequency**	**Weighted Column Percent (95% CI)**	**Weighted Column Percent (95% CI)**	**Weighted Column Percent (95% CI)**	**Weighted Column Percent (95% CI)**	**Weighted Column Percent (95% CI)**	**Weighted Column Percent (95% CI)**
I don't want to be tested for HIV	1957	36.5 (32.9–40.1)	47.9 (46.0–49.9)	47.9 (45.9–49.9)	31.3 (24.7–37.9)	38.4 (32.0–44.7)	36.7 (31.5–42.0)
Get tested at a routine visit with my regular health care provider	1813	42.6 (38.9–46.2)	40.6 (38.6–42.4)	39.0 (37.0–41.0)	49.2 (42.0–56.4)	48.0 (41.4–54.6)	42.9 (37.5–48.3)
Get tested at an urgent care or walk-in clinic	349	13.4 (10.8–16.1)	7.5 (6.4–8.6)	8.0 (6.9–9.2)	15.8 (10.2–	21.4) 10.9 (6.4–15.4)	12.1 (8.4–15.9)
Order an HIV test online and test myself at home	348	9.7 (7.5–12.0)	7.3 (6.3–8.3)	8.1 (7.0–9.2)	7.7 (3.5–11.9)	10.0 (6.2–13.8)	7.5 (4.4–10.7)
Pick up an HIV test at a pharmacy or other location and test myself at home	328	7.2 (5.3–9.0)	7.2 (6.2–8.1)	7.0 (6.0–7.9)	7.0 (3.7–10.3)	7.4 (4.3–10.5)	8.0 (5.0–11.1)
Get tested at an STD clinic	189	11.7 (9.2–14.2)	3.1 (2.4–3.9)	4.5 (3.5–5.5)	11.6 (6.5–16.6)	6.1 (3.0–9.2)	10.4 (6.8–14.0)
Get tested at a pharmacy	187	5.3 (3.6–7.0)	4.1 (3.4–4.9)	4.0 (3.2–4.8)	3.9 (1.4–6.3)	6.1 (2.8–9.4)	6.4 (3.7–9.0)
Get tested at a community-based organization	96	3.9 (2.4–5.4)	1.8 (1.3–2.4)	1.7 (1.2–2.2)	4.2 (1.4–6.9)	5.1 (1.6–8.7)	3.9 (1.5–6.3)
Get tested in the emergency room	114	3.1 (1.8–4.5)	2.7 (2.1–3.4)	2.5 (1.9–3.2)	6.4 (2.9–10.0)	1.0 (0.0–2.1)	3.4 (1.4–5.5)
Get tested at a public event like a health fair	54	2.0 (0.9–3.1)	1.1 (0.7–1.5)	1.1 (0.6–1.5)	2.5 (0.6–4.3)	2.1 (0.4–3.8)	2.0 (0.3–3.7)
Get tested at a student health clinic	41	5.1 (3.2–7.0)	0.4 (0.1–0.7)	1.3 (0.7–1.8)	5.6 (1.2–10.0)	3.9 (0.4–7.3)	2.7 (0.6–4.8)

*Participants could select up to 3 HIV testing preferences, including the option to not get tested. Selecting "I don't want to be tested for HIV" (n = 1957) precluded them from selecting other testing preferences. Preferences selected were not mutually exclusive. Percentages do not sum to 100%.