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Adolescents Living With or at Risk for HIV: A Pooled Descriptive Analysis of Studies From the Adolescent Medicine Trials Network for HIV/AIDS Interventions

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Conflicts of Interest

Dr. Arnold is a consultant on a project funded by Merck that is unrelated to the current project. All other authors have no potential conflicts of interest to declare.

Clinical Trial Registry Site and Number

Not applicable

Appendices

Appendix A. Supplemental Tables

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Abstract

Purpose: This study aims to describe the current cohort of Adolescent Medicine Trials Network for HIV/AIDS Interventions (ATN) research program participants and evaluate whether the ATN's current 5-year cycle recruited study participants who parallel the populations most impacted by HIV in the United States (US).

Methods: Harmonized measures across ATN studies collected at baseline were aggregated for participants aged 13–24 years. Pooled means and proportions stratified by HIV status (at risk for or living with HIV) were calculated using unweighted averages of study-specific aggregate data. Medians were estimated using a weighted median of medians method. Public use 2019 CDC surveillance data for state-level new HIV diagnoses and HIV prevalence among US youth aged 13–24 years were obtained for use as reference populations for ATN at-risk youth and youth living with HIV (YLWH), respectively.

Results: Data from 3185 youth at-risk for HIV and 542 YLWH were pooled from 21 ATN study phases conducted across the US. Among ATN studies tailored to at-risk youth, a higher proportion of participants were White and a lower proportion were Black/African American and Hispanic/Latinx compared to youth newly diagnosed with HIV in the US in 2019. Participants in ATN studies tailored to YLWH were demographically similar to YLWH in the US.

Discussion: The development of data harmonization guidelines for ATN research activities facilitated this cross-network pooled analysis. These findings suggest the ATN's YLWH are representative, but that future studies of at-risk youth should prioritize recruitment strategies to enroll more participants from African American and Hispanic/Latinx populations.

Keywords

Adolescent; Adolescent Medicine Trials Network for HIV/AIDS Interventions; Data Harmonization; HIV; Youth; Gay; Bisexual; Transgender

The Adolescent Medicine Trials Network for HIV/AIDS Interventions (ATN) research program aims to contribute to the scientific evidence-base of novel strategies to defeat the rising HIV epidemic among adolescents and young adults in the United States (US). Specifically, the goals of the ATN studies are to increase awareness of HIV status among at-risk youth, bend the infection rate curve towards zero through preventive interventions, and increase the numbers of youth living with HIV (YLWH) accessing each step of the care continuum [1]. ATN research is conducted through collaborations within the network and with researchers at institutions across the US. The current cycle of ATN (ATN IV) comprises three research program projects (or U19s) and a Coordinating Center (or U24) with over 20 study protocols across the network. Protocols include interventions for prevention of HIV infection for at-risk youth as well as interventions for reducing the impact of infection among YLWH. The populations of focus for many ATN studies are typically underrepresented in research but overrepresented in the epidemic, such as people of low socioeconomic status, LGBTQ+, and youth of color [1].

To optimize cross-network analyses of ATN study protocols, the ATN Analytic Committee published guidelines for harmonizing (i.e., standardizing) measures to be collected across

studies [2]. This set of harmonized measures facilitates the pooling of ATN data, allowing for the characterization of participants at risk for HIV and YLWH across ATN studies. This wealth of data describing large samples of at-risk youth and YLWH will provide guidance for future ATN recruitment efforts and help ensure that research findings are robust and applicable to the target population in the US.

The primary aim of this study was to describe the current cohort of ATN participants. The secondary aim was to evaluate whether ATN participants reflect the youth populations most impacted by HIV in the US based on key demographic characteristics by comparing the ATN youth at risk for HIV and YLWH to Centers for Disease Control and Prevention (CDC) data on US youth newly diagnosed with HIV and US YLWH, respectively.

METHODS

Study Population

Data were analyzed from all ATN IV studies with the exception of formative research activities, e.g., phase 1 studies, focus groups, etc. Each participating ATN study contributed aggregated baseline summary data for participants aged 13–24 years. The earliest data collection began in May 2017. Studies actively recruiting participants at the time of data compilation provided aggregated data for participants enrolled on or before March 31, 2021. Characteristics of participating studies (i.e., design, intervention, population) are summarized in Table A1. Among the participating studies, five recruited YLWH, 15 recruited youth at risk for HIV, and one recruited both YLWH and at-risk youth. Several studies exclusively enrolled specific populations, namely gay, bisexual, or transgender youth; young men who have sex with men; transwomen; same-sex male couples; YLWH failing antiretroviral therapy; young women at high risk for HIV; and youth experiencing homelessness. In this study, ‘at-risk youth enrolled in ATN studies’ is defined as a heterogeneous participant group pooled across studies tailored to specific at-risk populations. Eligibility criteria, geographic location of study sites, and sampling methods for each individual study protocol are summarized in Table A2 and described in detail elsewhere [3–22]. All studies were approved by the relevant institutional review boards.

CDC Surveillance Data

Public use 2019 CDC surveillance data for state-level new HIV diagnoses and YLWH among youth aged 13–24 years in the US [23] were obtained for use as reference populations for at-risk youth and YLWH participating in ATN studies, respectively. New HIV diagnoses were defined as the number of HIV infections confirmed by laboratory or clinical evidence in a calendar year and YLWH was defined using HIV prevalence data, which was the number of persons living with diagnosed HIV infection at the end of the specified year. All diagnoses reported to the CDC by the 50 states, the District of Columbia, and 6 U.S. dependent areas were included [24] (see Discussion for more details). The CDC data reported race and ethnicity categories as American Indian/Alaska Native, Asian/Pacific Islander, Black/African American, Hispanic/Latinx, White, and Multiracial. Assigned sex at birth was defined as Female and Male, and the geographic regions were defined as the US Census regions Midwest, Northeast, South, and West.

Study Measures

Key measures were collected in a uniform manner across ATN IV studies for five standard domains: demographics and socioeconomic characteristics; sexual behavior and risk; substance use and abuse; HIV-positive cascade; and HIV-negative cascade. A full listing of the ATN IV harmonized measures is defined elsewhere [2]. With the exception of HIV viral load and CD4 count data from one study, the utilized measures reflect self-reported responses to computer-assisted survey questions. In a few cases, if uncollected variables could be ascertained from a study's inclusion criteria, then these missing values were imputed based on the relevant study inclusion criteria.

In addition to the relevant harmonized measures, data were aggregated for a derived race/ethnicity variable based on the race and ethnicity values defined in the CDC surveillance data. The CDC based race/ethnicity derived variable was defined as follows: Participants reporting Hispanic/Latinx ethnicity, regardless of the selected race, were defined as "Hispanic/Latinx", those reporting non-Hispanic/Latinx ethnicity and a single race were defined as their reported race category, and those reporting non-Hispanic ethnicity and multiple races were defined as "Multiracial."

Pooling Methods

Each study provided aggregated data containing the harmonized measures from the standard domains for each of the participating study phases. Study-specific aggregated data included the mean, variance, minimum, and maximum values for continuous measures. If extreme minimum or maximum values for a variable were observed, the median and interquartile range were reported in addition to the mean and variance. For categorical variables, studies provided the count of affirmative responses for each response category. The number of participants eligible to respond to each question, which was less than or equal to the sample size (e.g., due to survey logic), and the number of missing values among participants eligible to respond were reported for all measures.

For each measure, the number of participants enrolled in studies that did not collect the measure was summed and defined as "not collected by study protocol". For measures where survey logic differed across protocols, pooled descriptive statistics were calculated using data as provided by the individual studies, and the total number ineligible to respond due to survey logic was summed and reported as "not applicable due to survey logic". For all categorical measures, response categories containing fewer than five participants after pooling were merged with similar categories, and combined counts and proportions were reported. Responses of "decline to answer", "refuse to answer", "don't know", and "missing" were collapsed into "missing" throughout due to small cell counts.

If by design a study had not collected information for a specific variable, it was excluded from the analyses for that measure. In cases of major discrepancies in the measurement of a variable across studies (e.g., STI testing in the past 6 months vs. past 12 months), the variable definition used by the greatest number of studies was retained, and data collected according to other definitions were excluded from the analyses and categorized as "not collected by study protocol".

Measures were omitted if reported by two or fewer studies (evaluated separately for at-risk and YLWH populations where applicable). In cases of minor discrepancies in measurement, variables were combined uniformly where possible. Particularly, responses to questions about sexual and substance use behaviors in the past 3 months and the past 4 months were combined throughout and labeled as “in the past 3 or 4 months”.

Statistical Analysis

Pooled descriptive statistics were computed for each harmonized measure. Pooled means and proportions were obtained using unweighted averages of study-specific aggregate data. For each measure, the pooled variance was estimated as the weighted average of study-specific sample variances, with weights specified as the Bessel-corrected sample sizes, plus the sample variance of the study-specific sample means. The pooled standard deviation (SD) was estimated as the square root of the pooled variance estimate. Study-specific empirical distributions for certain sexual behavior variables (number of sex partners in lifetime or past 3 to 4 months) were observed to be right skewed. For each of these measures, the median number of sex partners was estimated with a corresponding 95% confidence interval using the weighted median of medians method of [25]. All analyses were conducted in SAS version 9.4 (Cary, NC).

RESULTS

Overall, 3185 youth at risk for HIV and 542 YLWH enrolled in ATN studies between May 2017 and March 2021 were included in the pooled analysis. Demographic and socioeconomic characteristics of each group are shown in Table 1. The mean age of study participants was 21.0 years (SD=1.96 years) for at-risk youth and 21.7 years (SD=2.09 years) for YLWH. A plurality of at-risk youth were White (N=1477, 46.4%) and the majority of the YLWH were Black/African American (N=380, 70.1%). Both groups were mostly assigned male sex at birth (at-risk youth: N=2651, 83.2%; YLWH: N=440, 81.2%) and identified as gay, queer, same gender loving, or homosexual (at-risk youth: N=1877, 58.9%; YLWH: N=334, 61.6%).

Sexual behavior and risk measures for at-risk youth and YLWH participating in ATN studies are described in Table 2, respectively. The mean age at first time having sex was 16.0 years (SD=2.63 years) for at-risk youth and 15.4 years (SD=2.29 years) for YLWH. For youth at risk of HIV, 74.5% (N=1157) reported sexual intercourse without a condom in their lifetime and 42.0% (N=168) had condomless sex with a partner of unknown HIV status in the past 3 to 4 months. For YLWH, 82.2% (N=287) reported sexual intercourse without a condom in their lifetime.

Substance use and abuse measures for at-risk youth and YLWH participating in ATN studies are shown in Table 3. In both groups, 79.8% (at-risk youth: N=2478, YLWH: N=422) reported cannabis use at least once in their life. The most prevalent lifetime substance use reported by the at-risk youth were alcohol (N=1174, 88.0%), amphetamines (N=870, 28.0%), hallucinogens (N=758, 24.4%), cocaine (N=673, 21.7%), and inhalants (21.6%). For YLWH, these substances were alcohol (N=193, 74.8%), amphetamines (N=144, 27.2%), inhalants (N=141, 26.7%), and cocaine (N=133, 25.1%).

Table 4 compares the demographic characteristics of youth at risk for HIV in ATN studies with US youth newly diagnosed with HIV in the US in 2019. Compared to youth newly diagnosed with HIV in the US, a higher proportion of ATN participants at risk for HIV were non-Hispanic/Latinx White (N=1190, 15.7% vs. N=1159, 36.4%), and a lower proportion were non-Hispanic/Latinx African American/Black (N=3923, 51.7% vs. N=987, 31.0%) or Hispanic/Latinx (N=2094, 27.6% vs. N=475, 14.9%). Assigned sex at birth was similar between at-risk youth in ATN studies and youth newly diagnosed with HIV in the US, as 83.2% (N=2651) of ATN participants and 87.6% (N=6650) of the US youth were assigned male sex at birth. The geographic distribution of ATN participants was similar to that of newly diagnosed youth in the US, except there was a relatively larger proportion of ATN participants in the West (N=925, 29.0% vs. N=1294, 17.1%). This difference is also visible in Figure 1a, which maps the locations of ATN sites against the new HIV diagnosis rate in 2019 among US youth.

Demographic characteristics of YLWH in ATN studies are compared with YLWH in the US in 2019 in Table 4. Distributions of race/ethnicity and assigned sex at birth of ATN participants were similar to YLWH in the US. The majority of both ATN participants and YLWH in the US were assigned male sex at birth (N=440, 81.2%; N=24,429, 79.4%, respectively) and a higher proportion ATN participants were non-Hispanic/Latinx Black/African American (N=338, 62.4%; N=17,062, 55.4%). Figure 1b maps the locations of ATN sites against YLWH in the US. The ATN had a greater proportion of youth in the West compared to YLWH in the US (N=150, 27.7% vs. N=4903, 15.9%, respectively) and a smaller proportion of youth in the Northeast (N=44, 8.1% vs. N=5101, 16.6%).

The HIV negative cascade characteristics among at-risk ATN participants and the HIV positive cascade characteristics among YLWH in ATN studies are summarized in Supplemental Tables A3 and A4, respectively. Among the at-risk youth, 87.4% (N=2497) reported having had an HIV test and 73.2% (N=2178) reported they had an STI test in their lifetime. The most commonly reported STI diagnoses in the past 12 months were gonorrhea (N=71, 16.4%), chlamydia (N=67, 15.5%), and syphilis (N=37, 8.5%). Most of the at-risk youth reported they had never used pre-exposure prophylaxis (PrEP) (N=1941, 76.0%) and an even greater proportion reported they had never used post-exposure prophylaxis (PEP) (N=1449, 91.5%). Among those who reported barriers to PrEP uptake, 24.9% (N=530) reported they had never heard of PrEP and 24.8% (N=528) did not think it was necessary to use. For the HIV positive cascade, participants reported being diagnosed with HIV in years ranging from 1994 to 2020 with average year of HIV diagnosis being 2014. Most YLWH (81.3%, N=430) had seen a provider for HIV in their lifetime. Only 19.5% (N=103) of YLWH had an undetectable viral load though 82.0% (N=434) of YLWH stated they were on current antiretroviral (ARV) treatment (note that almost all YLWH studies' inclusion criteria was having a detectable viral load or being newly diagnosed). YLWH who were currently on ARV treatment missed at least one medication dose an average of 7.4 (SD=9.09) times in the past 30 days.

DISCUSSION

Overall, ATN IV studies recruited a population representative of YLWH in the US in terms of race/ethnicity, sex at birth, and geographic distribution. Among at-risk ATN participants, White youth were overrepresented in the ATN study population compared with youth newly diagnosed with HIV in the US and Black/African American youth were underrepresented. Both at-risk youth and YLWH living in the West were overrepresented in ATN studies relative to new and prevalent HIV diagnoses. Although the ATN prioritized research efforts in the South, where new diagnosis rates were markedly highest, at-risk ATN participants living in the South were underrepresented relative to new HIV diagnoses. These imbalances may be due to several factors. One study, Engaging HIV– youth (ATN 149), enrolled 1,487 participants, accounting for 46.7% of the pooled set of at-risk participants. This study enrolled 56.4% of its participants from sites in the West. While HIV prevalence in New York and Pennsylvania is relatively high (94.0 and 59.3 cases per 100,000 population, respectively), there were only two studies that recruited YLWH participants from New York and one study from Pennsylvania, likely contributing to the lower proportion of ATN YLWH in the Northeast compared to the comparator data. These population differences may also suggest that future studies focused on at-risk youth populations need to prioritize strategies to recruit underrepresented populations more efficiently, including the inclusion of more South and Northeast study sites.

This study provides data characterizing large samples of at-risk youth and YLWH in the US across important domains. The development of harmonization guidelines and the network structure of the ATN facilitated standardized collection and transfer of data, respectively, allowing for a comprehensive, detailed pooled analysis. The ATN cohort included populations that are typically underrepresented in research and overrepresented in the epidemic, such as those of low socioeconomic status, LGBTQ+, Asian Americans, African Americans, Hispanic/Latinx, and Native Americans/Alaskan Natives. In addition, published CDC data on HIV prevalence among US youth were utilized to make an appropriate comparison with ATN YLWH to evaluate how well the demographic characteristics of ATN participants align with the populations most impacted by HIV in the US.

The pooled at-risk population is diverse, and availability of published data on this age group limited our assessment of representativeness to demographic factors. Compared with the Keeping it LITE cohort study [26] of young sexual minority men and transgender individuals aged 13–34 years who reported one or more HIV risk behaviors (N=3,444, 96.7% HIV–), the proportion of ATN IV participants who were employed (53.7% ATN IV vs. 56.2% LITE) and had health insurance (78.8% ATN IV vs. 75.6% LITE) were similar, and fewer ATN IV at-risk participants attained a bachelor's degree or higher education (41.9% ATN IV vs. 48.5% LITE). Compared with the ATN protocol 125 cohort [27] of YLWH who received care at ATN clinical sites between February 2015 and February 2016 (N=820), a higher proportion of ATN IV participants reported marijuana use in the past 3 months (70.7% ATN IV vs. 61.9% ATN 125) while a smaller proportion reported alcohol use in the past 3 months (76.4% ATN IV vs. 80.9% ATN 125). Note that these cohort comparisons should be interpreted with caution since the pooled ATN data includes studies with various recruitment methods and inclusion/exclusion criteria (Table A2).

This study does not attempt to evaluate representativeness of individual ATN studies or to make cross-study comparisons because several studies were tailored to specific populations. Rather, one aim of this analysis was to evaluate if, collectively, these tailored research efforts led to a pooled network sample that was demographically and geographically representative of the HIV epidemic among US youth. Further, the findings of this study, in part, reflect the goals/prioritizations of ATN research efforts. For example, low baseline medication adherence among YLWH in ATN IV is partly explained by the fact that ATN studies tailor interventions to support adherence and specifically recruit youth experiencing barriers to adherence. The sample size of studies included in this pooled analysis varied, particularly across ATN studies enrolling at-risk youth. While a weighted analysis could be conducted in which each study contributes equal weight, the results of such an analysis would characterize a typical ATN study, and participants in smaller studies would be over-represented relative to participants in larger studies. Instead, we used an analysis where each individual contributes equal weight, in keeping with the goals of characterizing the set of participants reached by the ATN as a whole and assessing representativeness of the pooled participants.

This study has limitations. Availability of data for some measures was limited by variation in data collection across study protocols. The ATN harmonized measures collected on YLWH did not include HIV mode of acquisition, so adolescents with perinatally acquired HIV are not identified or characterized within the YLWH group. The demographic variables presented here were categorized to align with published CDC data and do not fully reflect some participants' identities (e.g., but not limited to, intersections of race and ethnicity, and gender and sex at birth). While CDC surveillance data are the most comprehensive source for the number and characteristics of YLWH in the US, there are limitations to this data source. Several factors impede surveillance efforts to count all HIV infections [24] including health care access, availability of testing, and differences in reporting regulations across states. It is possible that these factors lead to more pronounced undercounts of HIV infection for certain demographic or geographic groups. For this reason, CDC surveillance data reported in Table 4 should be interpreted as lower bounds for the true national burden of HIV infection. Note similar barriers may also influence participation in research. Thus, it is difficult to determine the extent to which limitations of CDC data collection procedures may impact the conclusions of this study.

Both CDC and ATN data collection could be modernized to better represent participants' gender, racial, and ethnic identities. Specifically, changes are needed to fully represent transgender youth in data, and to represent intersections of race and ethnicity, particularly for those who identify as Latinx. It is recommended that future data harmonization efforts define race and gender contextually, e.g., by offering participants opportunities to report multiple racial, ethnic, and cultural identities and to describe their identities qualitatively [28]. It is also recommended that future ATN cycles collect information on mode of HIV acquisition across all studies of YLWH.

This study was designed to describe the cohort of ATN IV participants. The ATN network reaches large groups of youth participants across the US. Data harmonization presents a unique opportunity to address questions important to specific adolescent populations, since

individual studies may not enroll many participants from a particular group of interest, and therefore only by harmonizing and pooling data across studies can we learn about these groups. Careful definition and consistent implementation of data harmonization procedures are needed to maximize this opportunity. It is recommended that future networks and ATN cycles define harmonization guidelines prior to developing individual study designs. Published harmonization guidelines for ATN IV [2] and the content of the present analysis may provide a template for and inform the development of future guidelines. Individual studies must balance the goals of collecting harmonized data, collecting study-aim-specific data, and minimizing respondent burden. Therefore, it is recommended that future research networks prioritize harmonized domains and measures that are central to network goals [2]. Support systems and resources for data harmonization are highly recommended to ensure feasibility of compliance with the harmonization efforts. Future analyses may consider leveraging the ATN IV harmonized data to expand the harmonization effort more broadly and perform additional pooled analyses.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Abbreviations

ATN	Adolescent Medicine Trials Network for HIV/AIDS Interventions
CDC	Centers for Disease Control and Prevention
NIH	National Institute of Health
PEP	Post-exposure prophylaxis
PrEP	Pre-exposure prophylaxis
SD	Standard deviation
STI	Sexually transmitted infections
US	United States
YLWH	Youth living with HIV

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IMPLICATIONS AND CONTRIBUTION

This study provides characterization of large, geographically and demographically diverse samples of youth at risk for HIV and youth living with HIV in the US across important domains. Findings can be leveraged to guide future study design and recruitment efforts.

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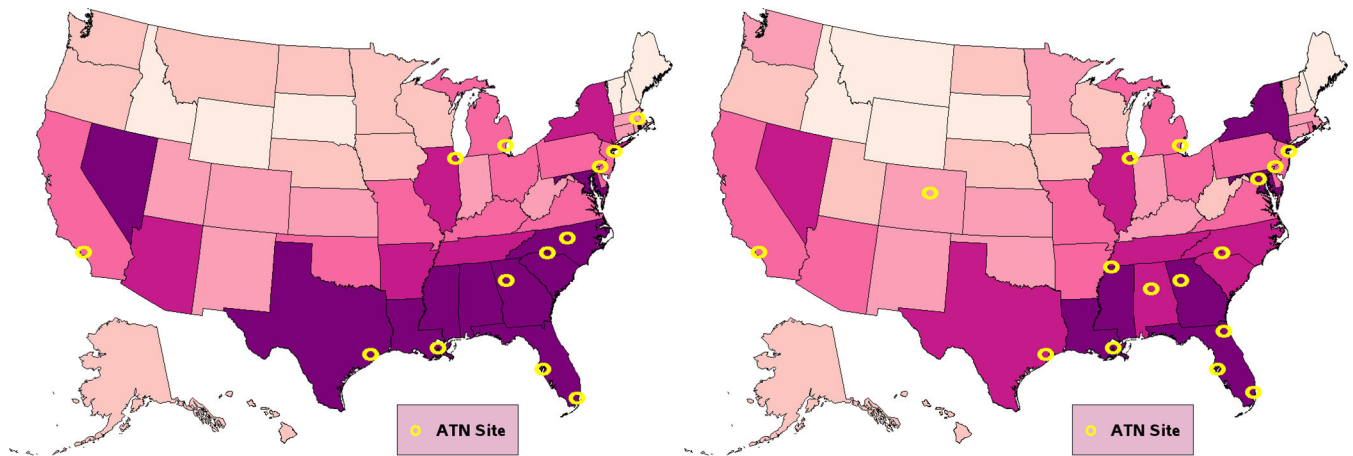


Figure 1a: New HIV diagnosis rate
(cases per 100,000 population)



Figure 1b: HIV prevalence
(cases per 100,000 population)

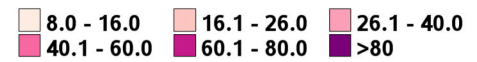


Figure 1:

Geographic reach of ATN studies^a that enrolled youth at risk for HIV and youth living with HIV between May 2017 and March 2021 mapped alongside new and prevalent HIV cases among US youth aged 13–24 years in 2019, respectively

^aFor 2 studies of at-risk youth and 1 study of youth living with HIV, study completion was virtual. Geographic locations of participants in these studies are not represented here.

Table 1. Self-reported demographic and socioeconomic characteristics by ATN groups enrolled between May 2017 and March 2021

Measure	Youth at risk for HIV in ATN studies		Youth Living with HIV in ATN studies	
	N=3185 n (%) ^d	N=542 n (%) ^d		
Age, mean (SD)	21.0 (1.96)	21.7 (2.09)		
13–18	476 (14.9)	52 (9.6)		
19–24	2689 (84.4)	490 (90.4)		
Missing	20 (0.6)	0 (0.0)		
Ethnicity				
Hispanic/Latinx	777 (24.4)	118 (21.8)		
Non-Hispanic/Latinx	2399 (75.3)	416 (76.8)		
Missing ^b	9 (0.3)	8 (1.5)		
Ethnic ancestry^c				
Caribbean	91 (27.2)	13 (37.1)		
Mexican	140 (41.9)	13 (37.1)		
Other	105 (31.4)	9 (25.7)		
Missing	6 (1.8)	0 (0.0)		
Not applicable ^d	1140	135		
Not collected by study protocol ^e	1711	372		
Race^c				
American Indian/Alaska Native	162 (5.1)	22 (4.1)		
Asian/Pacific Islander ^f	283 (8.9)	14 (2.6)		
Black/African American	1203 (37.8)	380 (70.1)		
White	1477 (46.4)	93 (17.2)		
Other	310 (9.7)	60 (11.1)		
Missing ^b	98 (3.1)	12 (2.2)		
Region				
Northeast	529 (16.6)	44 (8.1)		

Measure	Youth at risk for HIV in ATIN studies		Youth Living with HIV in ATIN studies	
	N=3185	n (%) ^d	N=542	n (%) ^d
South	1451	(45.6)	284	(52.4)
Midwest	275	(8.6)	64	(11.8)
West	925	(29.0)	150	(27.7)
Missing	5	(0.2)	0	(0.0)
Gender identity^c				
Female	269	(8.4)	102	(18.8)
Male	2443	(76.7)	404	(74.5)
Transgender female or transgender woman	126	(4.0)	22	(4.1)
Transgender male or transgender man	205	(6.4)	1	(0.2)
Genderqueer or gender nonconforming	251	(7.9)	12	(2.2)
Other	22	(0.7)	1	(0.2)
Missing	3	(0.1)	1	(0.2)
Assigned sex at birth				
Female	532	(16.7)	101	(18.6)
Male	2651	(83.2)	440	(81.2)
Missing	2	(0.1)	1	(0.2)
Sexual identity^c				
Bisexual	738	(23.2)	93	(17.2)
Gay, queer, same gender loving, or homosexual	1877	(58.9)	334	(61.6)
Straight or heterosexual	455	(14.3)	105	(19.4)
Pansexual	81	(2.5)	9	(1.7)
Another ^e	129	(4.1)	9	(1.7)
Missing ^b	7	(0.2)	3	(0.6)
Immediate family members aware of participant's sexual identity^h				
None	312	(11.2)	37	(8.5)
Some, but less than half	394	(14.2)	42	(9.7)
About half	176	(6.3)	16	(3.7)
More than half	661	(23.8)	113	(26.0)

Measure	Youth at risk for HIV in AITN studies		Youth Living with HIV in AITN studies	
	N=3185	n (%) ^d	N=542	n (%) ^d
All	1119 (40.3)		215 (49.4)	
Missing ⁱ	113 (4.1)		12 (2.8)	
Not applicable	12		9	
Not collected by study protocol	398		98	
Peers aware of participant's sexual identity^h				
None	115 (4.1)		19 (4.4)	
Some, but less than half	226 (8.1)		40 (9.2)	
About half	153 (5.5)		17 (3.9)	
More than half	893 (32.1)		63 (14.4)	
All	1364 (49.0)		291 (66.7)	
Missing ⁱ	32 (1.1)		6 (1.4)	
Not applicable	4		8	
Not collected by study protocol	398		98	
Currently enrolled in school				
Yes	1729 (54.3)		208 (38.4)	
No	1449 (45.5)		330 (60.9)	
Missing	7 (0.2)		4 (0.7)	
Current education level among those currently enrolled				
6th-12th grade	307 (18.3)		47 (22.6)	
GED program	50 (3.0)		20 (9.6)	
Technical or vocational school	46 (2.7)		13 (6.3)	
Two-year college	232 (13.8)		65 (31.3)	
Four-year college or higher	1030 (61.4)		60 (28.8)	
Missing	12 (0.7)		3 (1.4)	
Did not report being currently enrolled	1403		334	
Not collected by study protocol	105		0	
Highest education level completed among not currently enrolled				
None, no formal schooling	3 (0.2)		1 (0.3)	
6th-8th grade	20 (1.4)		9 (2.7)	

Measure	Youth at risk for HIV in ATIN studies		Youth Living with HIV in ATIN studies	
	N=3185	n (%) ^a	N=542	n (%) ^a
9th-11th grade	215	(15.4)	71	(21.5)
High school diploma	385	(27.6)	110	(33.3)
High school certificate of completion (no diploma)	15	(1.1)	11	(3.3)
GED	106	(7.6)	30	(9.1)
Some college, technical school, or vocational school	221	(15.8)	60	(18.2)
Technical or vocational school graduate	31	(2.2)	14	(4.2)
Two-year college graduate	93	(6.7)	8	(2.4)
Four-year college graduate or higher	298	(21.3)	16	(4.8)
Missing	10	(0.7)	0	(0.0)
Did not report being currently out of school	1683		212	
Not collected by study protocol	105		0	
Currently employed				
Yes	1616	(53.7)	277	(51.1)
No	1357	(45.1)	252	(46.5)
Missing ^b	38	(1.3)	13	(2.4)
Not collected by study protocol	174		0	
Current employment type				
Full-time	694	(43.0)	148	(53.4)
Part-time	918	(56.8)	128	(46.2)
Missing	3	(0.2)	1	(0.4)
Did not report being currently employed	1396		265	
Not collected by study protocol	174		0	
Health insurance status				
Yes	2317	(78.8)	419	(77.3)
No	453	(15.4)	78	(14.4)
Missing ^b	169	(5.8)	45	(8.3)
Not collected by study protocol	246		0	

^aExcept where noted otherwise

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^qIncludes responses 'Missing' and 'Unknown'.

^cThe sum of categories may exceed the column total because some studies collected only one response per participant, while other studies offered participants the option to 'select all that apply'.

^dParticipants in studies that collected ethnic ancestry data who self-identified as Non-Hispanic/Latinx.

^e443 at-risk participants in this category identified as Hispanic/Latinx; 1,261 self-identified as Non-Hispanic/Latinx; and 7 had missing or unknown values for Ethnicity. 83 YLWH in this category identified as Hispanic/Latinx; 285 identified as non-Hispanic/Latinx; and 4 had missing or unknown values for ethnicity.

^fOne study collected Asian/Pacific Islander as a single category.

^gIncludes responses 'Asexual/Other', 'Other', and 'Unsure/Questioning/I don't know'.

^hThree studies asked this question only of participants who reported a sexual identity other than 'Straight or heterosexual'.

ⁱIncludes responses 'Missing' and 'Unsure'.

Self-reported sexual behavior and risk by ATN groups enrolled between May 2017 and March 2021

Table 2.

Measure	Youth at risk for HIV in ATN studies		Youth Living with HIV in ATN studies	
	N=3185 n (%) ^d	N=542 n (%) ^d		
Ever had sex				
Yes	2489 (97.6)	507 (93.5)		
No	52 (2.0)	26 (4.8)		
Missing	8 (0.3)	9 (1.7)		
Not collected by study protocol	636	0		
Age at first time sex, mean (SD)	16.0 (2.63)	15.4 (2.29)		
Missing ^b	90 (4.0)	21 (6.1)		
Did not report ever having sex	40	10		
Not collected by study protocol	881	186		
Who had sex with in lifetime				
Females	311 (14.5) ^c	18 (5.2) ^d		
Males	1041 (48.7) ^e	185 (53.5) ^f		
Females and males	667 (31.2) ^{c,e}	126 (36.4) ^{d,f}		
Another response	25 (1.2) ^g	3 (0.9) ^h		
Missing	95 (4.4)	14 (4.0)		
Did not report ever having sex	60	10		
Not collected by study protocol	986	186		
Female sex partners in lifetime among those with female partners ever, mean (SD)	14.0 (56.00)	7.2 (25.41)		
Median (95% CI)	5 (2.5)	3 (2.3) ⁱ		
Missing ^j	75 (4.5)	5 (1.7)		
Did not report ever having sex with female partner	525	54		
Not collected by study protocol	986	186		
Female sex partners in past 3 to 4 months, mean (SD)^{k,l}	2.3 (1.90)	0.4 (1.42)		
Median (95% CI)	1 (0.1)	0 (0.1)		

	Youth at risk for HIV in ATIN studies	Youth Living with HIV in ATIN studies
Measure	N=3185	N=542
Missing ^g	n (%) ^d	n (%) ^d
Not applicable due to survey logic	16 (1.4)	3 (2.1)
Not collected by study protocol	1325	225
	701	173
Male sex partners in lifetime among those with male partners ever, mean (SD)	21.3 (74.46)	42.5 (92.95)
Median (95% CI)	7 (6.7)	14 (10,23) ⁱ
Missing ^g	122 (5.7)	30 (8.5)
Did not report ever having sex with male partner	66	4
Not collected by study protocol	986	186
Male sex partners in past 3 to 4 months, mean (SD)^{k,l}	3.2 (7.24)	5.1 (11.47)
Median (95% CI)	2 (2.2)	2 (2,3)
Missing ^g	33 (1.5)	5 (1.4)
Not applicable due to survey logic	529	23
Not collected by study protocol	416	173
Transgender female sex partners in lifetime among those with transgender female partners ever, mean (SD)	1.5 (0.94)	—
Missing	1 (2.7)	—
Did not report ever having sex with transgender female partner	577	—
Not collected by study protocol	2571	—
Transgender female sex partners in past 3 months, mean (SD)	0.6 (1.09)	—
Not applicable due to survey logic	758	—
Not collected by study protocol	2318	—
Transgender male sex partners in lifetime among those with transgender male partners ever, mean (SD)	2.0 (1.87)	—
Missing	1 (1.3)	—
Did not report ever having sex with transgender male partner	537	—
Not collected by study protocol	2571	—
Transgender male sex partners in past 3 months, mean (SD)	0.5 (0.89)	—
Missing	1 (0.7)	—
Not applicable due to survey logic	654	—
Not collected by study protocol	2397	—

Measure	Youth at risk for HIV in ATIN studies		Youth Living with HIV in ATIN studies	
	N=3185 n (%) ^d		N=542 n (%) ^d	
Substance use before last sexual intercourse^k				
Yes	928 (38.7)		162 (46.8)	
No	1452 (60.5)		184 (53.2)	
Missing	21 (0.9)		0 (0.0)	
Not applicable due to survey logic	77		10	
Not collected by study protocol	707		186	
Sex without condom in lifetime among those who reported ever having sex				
Yes	1157 (74.5)		287 (82.2)	
No	286 (18.4)		42 (12.0)	
Missing	111 (7.1)		20 (5.7)	
Did not report ever having sex	31		7	
Not collected by study protocol	1600		186	
Sex without condom in past 3 to 4 months, HIV negative partner^{k,l}				
Yes	246 (68.3)		—	
No	112 (31.1)		—	
Missing	2 (0.6)		—	
Not applicable due to survey logic	66		—	
Not collected by study protocol	2759		—	
Sex without condom in past 3 to 4 months, HIV unknown partner^{k,l}				
Yes	168 (42.0)		—	
No	227 (56.8)		—	
Missing	5 (1.3)		—	
Not applicable due to survey logic	66		—	
Not collected by study protocol	2719		—	
Sex without condom in past 3 to 4 months, HIV Positive partner^{k,l}				
Yes	65 (3.6)		82 (24.8)	
No	1709 (95.5)		245 (74.0)	
Missing	16 (0.9)		4 (1.2)	

	Youth at risk for HIV in ATIN studies	Youth Living with HIV in ATIN studies
Measure	N=3185 n (%) ^a	N=542 n (%) ^a
Not applicable due to survey logic	123	25
Not collected by study protocol	1272	186

^aExcept where noted otherwise

^bIncludes missing and responses less than 9. Responses less than 9 were recoded to missing, as these do not reflect age of first consensual sex.

^cIncludes responses 'Females' and 'Cisgender Women (female sex at birth)'.

^dIncludes responses 'Females' and 'Females (including nonbinary partners who have vaginas)'.

^eIncludes responses 'Males' and 'Cisgender Men (male sex at birth)'.

^fIncludes responses 'Males' and 'Males (including nonbinary partners who have penises)'.

^gIncludes participants who did not indicate "Females", "Cisgender Women", "Males", "Cisgender Men", "Females and Males", or "Cisgender Women and Cisgender Men", but who did indicate "Transgender Women", "Transgender Men", "Transgender partners", "Non-binary individuals", or "People who identify their gender in some other way".

^hIncludes participants who did not indicate "females", "males", or "females and males", but who did indicate "transgender partners".

ⁱThree studies that focused on YLWH contributed median data. We are reporting the median (min, max) of the three observed study-specific medians.

^jIncludes responses 'Don't Know' and 'Missing'.

^kSurvey logic that determined whether this question was presented differed across studies.

^lOne study (focused on at-risk youth) reported this variable for casual partners specifically.

Table 3. Self-reported substance use and abuse by ATN groups enrolled between May 2017 and March 2021

Measure	Youth at risk for HIV in ATN studies		Youth Living with HIV in ATN studies	
	N=3185 n (%) ^d	N=542 n (%) ^d		
Lifetime tobacco use				
Yes	838 (51.8)	136 (52.7)		
No	769 (47.5)	120 (46.5)		
Missing	12 (0.7)	2 (0.8)		
Not collected by study protocol	1566	284		
Tobacco use in past 3 to 4 months^{b, c}				
Never	1121 (51.1)	181 (43.1)		
Once or twice	181 (8.3)	28 (6.7)		
Monthly	60 (2.7)	14 (3.3)		
Weekly	59 (2.7)	10 (2.4)		
Daily or almost daily	764 (34.8)	183 (43.6)		
Missing	8 (0.4)	4 (1.0)		
Did not report ever using tobacco	577	122		
Not collected by study protocol	415	0		
Lifetime alcohol use				
Yes	1174 (88.0)	193 (74.8)		
No	145 (10.9)	63 (24.4)		
Missing	15 (1.1)	2 (0.8)		
Not collected by study protocol	1851	284		
Alcohol use in past 3 to 4 months^c				
Never	448 (17.8)	63 (13.2)		
Once or twice	202 (8.0)	74 (15.5)		
Monthly	989 (39.2)	184 (38.6)		
Weekly	656 (26.0)	110 (23.1)		
Daily or almost daily	218 (8.7)	40 (8.4)		
Missing	7 (0.3)	6 (1.3)		

Measure	Youth at risk for HIV in ATIN studies		Youth Living with HIV in ATIN studies	
	N=3185 n (%) ^d		N=542 n (%) ^d	
Did not report ever using alcohol	145		65	
Not collected by study protocol	520		0	
Binge drinking^{c, d}				
Never	886 (35.0)		125 (40.5)	
Once or twice	285 (11.3)		0 (0.0)	
Less than monthly	487 (19.2)		100 (32.4)	
Monthly	504 (19.9)		44 (14.2)	
Weekly	310 (12.2)		30 (9.7)	
Daily or almost daily	43 (1.7)		4 (1.3)	
Missing	16 (0.6)		6 (1.9)	
Not applicable due to survey logic	654		60	
Not collected by study protocol	0		173	
Lifetime cannabis use				
Yes	2478 (79.8)		422 (79.8)	
No	607 (19.5)		99 (18.7)	
Missing	21 (0.7)		8 (1.5)	
Not collected by study protocol	79		13	
Cannabis use in past 3 to 4 months^c				
Yes	1825 (81.4)		383 (88.0)	
No	411 (18.3)		51 (11.7)	
Missing	6 (0.3)		1 (0.2)	
Did not report ever using cannabis	528		107	
Not collected by study protocol	415		0	
Lifetime cocaine use				
Yes	673 (21.7)		133 (25.1)	
No	2411 (77.6)		393 (74.3)	
Missing	22 (0.7)		3 (0.6)	
Not collected by study protocol	79		13	
Cocaine use in past 3 to 4 months^c				

Measure	Youth at risk for HIV in AITN studies		Youth Living with HIV in AITN studies	
	N=3185	N=542	N=3185	N=542
	n (%) ^a	n (%) ^a	n (%) ^a	n (%) ^a
Yes	257 (39.0)	68 (46.6)		
No	402 (61.0)	78 (53.4)		
Did not report ever using cocaine	2071	396		
Not collected by study protocol	455	0		
Lifetime amphetamine use				
Yes	870 (28.0)	144 (27.2)		
No	2191 (70.5)	381 (72.0)		
Missing	45 (1.4)	4 (0.8)		
Not collected by study protocol	79	13		
Amphetamine use in past 3 to 4 months^c				
Yes	399 (45.0)	85 (54.1)		
No	488 (55.0)	72 (45.9)		
Did not report ever using amphetamines	1843	385		
Not collected by study protocol	455	0		
Lifetime inhalants use				
Yes	663 (21.6)	141 (26.7)		
No	2371 (77.3)	383 (72.4)		
Missing	32 (1.0)	5 (0.9)		
Not collected by study protocol	119	13		
Inhalants use in past 3 to 4 months^c				
Yes	373 (52.7)	87 (56.5)		
No	334 (47.2)	67 (43.5)		
Missing	1 (0.1)	0 (0.0)		
Did not report ever using inhalants	2022	388		
Not collected by study protocol	455	0		
Lifetime sedative use				
Yes	559 (18.2)	95 (18.0)		
No	2462 (80.3)	429 (81.1)		
Missing	45 (1.5)	5 (0.9)		

Measure	Youth at risk for HIV in ATN studies		Youth Living with HIV in ATN studies	
	N=3185	n (%) ^a	N=542	n (%) ^a
Not collected by study protocol	119		13	
Sedative use in past 3 to 4 months^c				
Yes	220 (38.1)		51 (47.2)	
No	357 (61.9)		57 (52.8)	
Did not report ever using sedatives	2153		434	
Not collected by study protocol	455		0	
Lifetime hallucinogen use				
Yes	758 (24.4)		92 (17.4)	
No	2318 (74.6)		434 (82.0)	
Missing	30 (1.0)		3 (0.6)	
Not collected by study protocol	79		13	
Hallucinogen use in past 3 to 4 months^c				
Yes	283 (38.5)		40 (38.1)	
No	453 (61.5)		65 (61.9)	
Did not report ever using hallucinogens	1994		437	
Not collected by study protocol	455		0	
Lifetime opioid use				
Yes	506 (16.3)		78 (14.7)	
No	2579 (83.0)		448 (84.7)	
Missing	21 (0.7)		3 (0.6)	
Not collected by study protocol	79		13	
Opioid use in past 3 to 4 months^c				
Yes	192 (35.3)		33 (36.3)	
No	352 (64.7)		58 (63.7)	
Did not report ever using opioids	2186		451	
Not collected by study protocol	455		0	

^aExcept where noted otherwise

^bOne study focused on at-risk youth and two studies focused on YLWH collected only 'Daily' or 'Never' responses. All other participants in these studies were counted under 'Not Collected'.

Survey logic that determined whether this question was presented differed across studies.
One study defined binge drinking as 6 or more drinks; the remaining studies defined binge drinking as 4 or more drinks for female-identifying participants and 5 or more drinks for male-identifying participants.

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Demographic characteristics among youth enrolled in ATN studies between May 2017 and March 2021 and US youth aged 13–24 years in 2019

Table 4.

Characteristic	New HIV diagnoses among youth in US				Youth living with HIV in US	
	Youth at risk for HIV in ATN studies N=3185 n (%)	New HIV diagnoses among youth in US N=7588 n (%)	Youth living with HIV in ATN studies N=542 n (%)	Youth living with HIV in US N=30782 n (%)		
Race/Ethnicity						
American Indian/Alaska Native	32 (1.0)	46 (0.6)	5 (0.9)	125 (0.4)		
Asian/Pacific Islander ^a	182 (5.7)	134 (1.8)	7 (1.3)	568 (1.8)		
Black/African American	987 (31.0)	3923 (51.7)	338 (62.4)	17062 (55.4)		
Hispanic/Latinx	475 (14.9)	2094 (27.6)	104 (19.2)	7623 (24.8)		
White	1159 (36.4)	1190 (15.7)	49 (9.0)	4157 (13.5)		
Multiracial	242 (7.6)	201 (2.6)	29 (5.4)	1241 (4.0)		
Other	56 (1.8)	N/A	4 (0.7)	N/A		
Missing	52 (1.6)	N/A	6 (1.1)	6 (0.0)		
Assigned Sex at Birth						
Female	532 (16.7)	938 (12.4)	101 (18.6)	6353 (20.6)		
Male	2651 (83.2)	6650 (87.6)	440 (81.2)	24429 (79.4)		
Missing	2 (0.1)	N/A	1 (0.2)	N/A		
Region						
Northeast	529 (16.6)	971 (12.8)	44 (8.1)	5101 (16.6)		
South	1451 (45.6)	4236 (55.8)	284 (52.4)	16158 (52.5)		
Midwest	275 (8.6)	1087 (14.3)	64 (11.8)	4620 (15.0)		
West	925 (29.0)	1294 (17.1)	150 (27.7)	4903 (15.9)		
Missing	5 (0.2)	N/A	0 (0.0)	N/A		

^aOne study collected Asian/Pacific Islander as a single category.