HIV Testing and PrEP Use in a National Probability Sample of Sexually Active Transgender People in the United States

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Background: HIV testing and pre-exposure prophylaxis (PrEP) are effective HIV prevention strategies often underused by transgender people.

Methods: Recruitment occurred in 2 phases to identify transgender respondents in a probability sample of adults in the United States. Transgender respondents completed a self-administered paper or web-based survey designed to assess transgender population health. Sexually active respondents (HIV-negative and had sex in the 5 years previously, N = 190) and a subsample of those at risk for sexual HIV acquisition (sex with cisgender men or transgender women, n = 120) were included in analyses.

Results: Of the full sample of sexually active respondents, those who were transfeminine were less likely to be familiar with PrEP; most (72%) reported favorable attitudes toward PrEP. Of those at risk for HIV acquisition, 23% had never tested for HIV. Respondents of color were more likely than white respondents to meet Centers for Disease Control and Prevention recommendations for HIV testing. Respondents who met Centers for Disease Control and Prevention recommendations for HIV testing were more likely to report looking online for PrEP-related health information. Few respondents reported currently taking PrEP (3%); those who reported higher levels of nonaffirmation of their gender identity were less likely to currently use PrEP.

Discussion: These findings may indicate some success of HIV testing outreach programs that prioritize people at higher risk for acquiring HIV, focusing on those who are vulnerable to structural marginalization. Ongoing public health efforts are needed to increase HIV testing and PrEP awareness among transgender adults, who are disproportionately impacted by HIV.

Key Words: HIV testing, pre-exposure prophylaxis, transgender, PrEP knowledge, PrEP use, probability sample

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INTRODUCTION

Transgender people (individuals whose gender identity differs from sex assigned at birth) are disproportionately impacted by HIV,1 with prevalence estimates of approximately 14% among transgender women and 3% among transgender men in the United States.2,3 HIV prevention and treatment efforts, such as HIV testing and pre-exposure prophylaxis (PrEP), are effective HIV prevention strategies often underused in transgender populations. The Centers for Disease Control and Prevention (CDC) recommends that at-risk individuals get tested every 3–6 months,4 but HIV testing remains lower among transgender people than other key populations.5,6

PrEP is an effective HIV prevention method when taken as prescribed.7 To date, preexposure prophylaxis initiative (iPrEx) is the only clinical trial of PrEP that reported results specific to transgender women;7 no clinical trials to date have reported data on transgender men. Although the results of iPrEx were initially reported without disaggregating transgender women from men who have sex with men, a subanalysis of iPrEx found no efficacy on an intention-to-treat basis among 339 transgender women enrolled,8 likely because of low adherence. Furthermore, hormone use was associated with lower TFV-DP levels. Currently, high levels of adherence to oral PrEP are recommended for transgender women.9,10 PrEP data in transgender men remain sparse. A recent online survey of 857 transmasculine individuals who have sex with men found that of those who were HIV-negative, 52.5% met PrEP indications and 33.3% reported lifetime PrEP use (21.8% current and 11.5% past).11 In another recent study, of 439 transmasculine individuals who were eligible for PrEP, only 11% had received a PrEP prescription.12

Unique barriers and facilitators to HIV testing and PrEP uptake and adherence have been reported among transgender people.13 HIV testing rates among transgender people are inadequate given their risk for HIV, suggesting that culturally tailored programs are needed.14 PrEP knowledge has been demonstrated to be lower among transgender people than among cisgender men who have sex with men.15,16 Attitudes toward PrEP are often mixed in studies of transgender people, with fear of negative interactions with hormones and HIV
stigma inhibiting uptake.17 Past and anticipated experiences of trans-related stigma and discrimination in health care settings are also significant barriers,16,18 and facilitators include colocation of HIV testing and PrEP care with transition-related care, such as hormone prescription and monitoring.19 Access to gender-affirming services has been shown to be critical in HIV-related and health-related interventions for transgender people.20–22

To date, studies of HIV testing and PrEP among transgender people have been conducted using convenience samples or have been restricted to small geographic regions. We present results from the first national probability sample in the United States to characterize HIV testing and PrEP attitudes and uptake among transgender individuals.

METHODS
Sample and Procedure
Recruitment occurred in 2 phases using a US probability sample of adults aged 18 years and older. In phase 1, a national probability sample was screened by asking respondents’ sex assigned at birth and gender identity and inviting transgender people (defined as individuals whose gender identity is different from their sex assigned at birth) to participate in phase 2. In phase 2, transgender individuals completed a self-administered paper or web-based survey. Recruitment was conducted by Gallup, a survey research organization, and occurred between April 2016 and August 2016 and between June 2017 and December 2018. Sampling targeted the total US population using random digit dialing of cell phones and landlines in the first recruitment period and using address-based sampling in the second period. In total, 432,251 individuals were screened, of which 929 identified as transgender (0.21%) in phase 1. Of those, 668 (72%) agreed to participate and proceeded to phase 2, and 46.9% of them completed the survey. The total completion rate (defined as completed surveys divided by all screened eligible) was 33%. The final data set includes 274 respondents representing the US population of transgender individuals as defined by our measures. Data were weighted to account for nonresponse from the general population sample of all respondents based on census data. Because no census data or other national probability sample exists, the second weighting process used data on demographics of transgender respondents using Gallup data, which included nonrespondents to the survey. More details about the methods are available online.23

Respondents were classified as transgender if their gender identity was different from their sex assigned at birth. We defined transgender as transfeminine, respondents assigned male at birth, and transmasculine, respondents assigned female at birth.

HIV Status
HIV status was assessed using 2 measures to maximize the sample size: by indicating “HIV/AIDS” to “Have you EVER been told by a doctor or health professional that you had any of the following?” and/or indicating “I’m HIV-positive” to “About how often do you get tested for HIV?”

Sexual Activity in the Past 5 Years
Respondents were asked “In the past 5 years, who did you have sex with? By sex we mean any activity you personally define as sexual activity. Please mark all that apply.” Responses included: “Women, Non-Transgender,” “Men, Non-Transgender,” “Transgender Women/Male-to-Female,” “Transgender Men/Female-to-Male,” and “I have not had sex with anyone in the past 5 years.”

Outcomes
HIV Testing Frequency
HIV testing frequency was assessed by asking, “About how often do you get tested for HIV?” Responses were categorized as meeting CDC recommendations (“About once every 1–3 months,” “About once every 6 months,” and “About once a year”), tested less frequently than recommended, or never having been tested.4

PrEP Use
Respondents were asked if they were “currently taking Truvada as PrEP.”

PrEP Familiarity
Respondents were asked how familiar they were with PrEP. Responses were dichotomized into “familiar” (“Very familiar,” “Somewhat familiar,”) or “Not at all familiar.”

Attitudes Toward PrEP
Respondents were asked: “Are you for or against HIV-negative people taking Truvada as PrEP to prevent the transmission of HIV?” Responses were dichotomized into “I am for it” and not for it (“I am against it,” “I have mixed feelings about it,” “I don’t have an opinion,” or “I don’t know enough about it”).

Sociodemographic Variables
Age
Age was calculated from the respondent’s birth year obtained from their response to “In what year were you born?”

Person of Color
Respondents were asked “Which of the following describes your race/ethnicity? Please mark all that apply.” Categories were collapsed into person of color (“black/African American,” “Hispanic, Latino, or Spanish origin,” “Asian/Asian American,” “Middle Eastern/North African,”
“Native Hawaiian/Pacific Islander,” “American Indian or Alaskan Native,” “Multiracial,” and “white”).

**Education Level**

Education level was dichotomized to high school or less ("less than high school diploma" or "high school degree or diploma") and more than high school ("technical/vocational school," "some college," "college graduate," or "postgraduate work or degree").

**Urbanicity**

Respondents’ zip codes were used to calculate urbanicity scores based on the 2010 USDS Rural-Urban Commuting Area coding system.24 Scores were dichotomized to "urban" (1–3) and "nonurban" (>3).

**Poverty**

Levels of poverty were calculated based on respondents’ reported household income range and the number of people living on that household income. Poverty categories were based on weighted Census estimates for poverty thresholds in 2018.25 Respondents were categorized as living in poverty (<100% federal poverty level) or not in poverty (>100% federal poverty level).

**Psychosocial Variables**

**HIV Worry**

Respondents were asked “How often do you worry that you might get HIV?” Responses were dichotomized to “Never” and sometimes or more (“Sometimes,” “Often,” or “Always”).

**Online LGBT Health**

Respondents were asked “During the past 12 months, have you looked for information online about certain health or medical issues?” Responses were dichotomized to those who chose “Yes, an lesbian, gay, bisexual, and transgender (LGBT), or transgender-specific, website” vs. others.

**Nonaffirmation of Gender Identity**

A 5-point scale assessing respondents’ experiences of their gender identity not being understood or accepted by others, created as a mean score of 6 items using a 5-point scale ("strongly disagree" to “strongly agree”).26 Missing individual scale items were imputed using predictive mean matching.27

**Data Analysis**

We excluded from the analysis respondents living with HIV (n = 13, 5.4%) and those who reported not having sex within 5 years (n = 74, 27.7%). We used 2 sample definitions: (1) sample 1, for assessing knowledge and attitudes about PrEP, we used a sample of 190 respondents, or 67.4% of the total sample, after excluding those living with HIV and those who had no sex in 5 years; and (2) sample 2, is a subsample of 112 respondents (45.0% of the total sample) at high risk for HIV transmission, was defined as those not living with HIV and who had sex with cisgender men and/or transgender women within 5 years. Table 1 shows sociodemographic characteristics of sample 1, HIV-negative, and sexually active transgender individuals. There were no significant differences between sample 1 and the subsample (sample 2) in demographic characteristics reported in Table 1.

We report weighted prevalence estimates and 95% confidence intervals (CIs) for HIV testing and PrEP use, familiarity, and attitudes across the entire sample and by sex assigned at birth. Bivariate logistic regression analysis was conducted to evaluate associations of sociodemographic and psychosocial variables with familiarity and attitudes toward PrEP. We performed multiple logistic regression analysis to examine HIV testing, familiarity with PrEP, and attitudes toward PrEP predicted by the demographic and psychosocial variables. We performed bivariate analyses for PrEP use because of the small sample size of people on PrEP. Analyses were performed using Stata 14.2.

### RESULTS

**HIV Testing (Sample 2)**

Among respondents who had sex with cisgender men and/or transgender women, nearly half (46.4%, 95% CI: 35.0% to 58.2%) met CDC recommendations for HIV testing of at least annually, but 22.8% (95% CI: 14.3% to 34.3%) had never tested for HIV, with no significant differences between transmasculine and transfeminine people (Table 2). Multiple logistic regression results (Table 4) showed that respondents of color were more likely than white respondents to meet HIV testing recommendations (odds ratio [OR]: 8.2, CI: 2.3 to 28.8). Respondents whose highest education level is high school or less and respondents who never looked online at an LGBT-specific or trans-specific website for health information were less likely to meet HIV testing recommendations (OR: 0.2, CI: 0.1 to 0.6; OR: 0.2, CI: 0.1 to 0.6, respectively).

### TABLE 1. Demographic Characteristics of Transgender Individuals at Risk for HIV: the US National Probability Sample

| Sample 1 (N = 190)* | N | Weighted % (95% CI) |
|---------------------|---|-------------------|
| Gender identity     |   |                   |
| Transmasculine/female at birth | 99 | 56.2 (46.9 to 65.2) |
| Transfeminine/male at birth    | 91 | 43.8 (34.8 to 53.1) |
| Age (mean)          | 190 | 33.1 (30.8 to 35.4) |
| Race/ethnicity      |   |                   |
| White               | 140 | 58.8 (49.0 to 67.9) |
| POC                 | 50  | 41.2 (32.1 to 51.0) |
| Education           |   |                   |
| High school or less | 37  | 41.9 (32.5 to 51.9) |
| More than high school | 152 | 58.1 (48.1 to 67.5) |
| Urbanicity          |   |                   |
| Urban               | 152 | 82.8 (75.0 to 88.5) |
| Nonurban            | 38  | 17.2 (11.5 to 25.0) |
| Poverty             |   |                   |
| In poverty          | 43  | 23.1 (16.2 to 32.0) |
| Not in poverty      | 147 | 76.9 (68.0 to 83.8) |

Sample 1 includes HIV-negative individuals who had any sexual activity in the 5-year period before taking the survey.

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TABLE 2. HIV Testing and PrEP Use Among Transgender Individuals at Risk for HIV, by Gender Identity: the US National Probability Sample

| Sample 2* (N = 112) | Transmasculine (N = 55) | Transfeminine (N = 57) | F-Statistic |
|----------------------|------------------------|------------------------|-------------|
| Tested for HIV        | n                      | Weighted % (95% CI)    | n Weighted % (95% CI) | n Weighted % (95% CI) |             |
| Never                | 25                     | 22.8 (14.3 to 34.3)    | 14              | 26.8 (14.6 to 44.0)    | 11           | 19.0 (8.9 to 36.0) | 0.36         |
| Yes, less than once a year | 34               | 30.8 (21.2 to 42.6)    | 15              | 27.4 (15.2 to 44.2)    | 19           | 34.0 (20.4 to 51.0) |             |
| Yes, met CDC recommendation (once a year or more) | 52             | 46.4 (35.0 to 58.2)    | 25              | 45.8 (30.2 to 62.3)    | 27           | 47.0 (31.2 to 63.4) |             |
| Currently taking Truvada as PrEP | 5               | 2.7 (1.0 to 7.2)       | 2               | 3.2 (0.7 to 13.3)      | 3            | 2.3 (0.7 to 7.6)   | 0.12         |

*Sample 2 includes HIV-negative individuals who had any sexual activity with cisgender men and/or transgender women in the 5-year period before taking the survey.

PrEP Use (Sample 2)
Among respondents who had sex with cisgender men and/or transgender women, only 5 respondents (2.7%, CI: 1.0% to 7.2%; Table 2) reported currently taking Truvada as PrEP, with no significant differences between transmasculine and transfeminine respondents. Bivariate analyses showed that PrEP use was associated with meeting HIV testing recommendations (design-based F = 4.2, P = 0.04) and a lower score of nonaffirmation of gender identity (design-based F = 10.6, P = 0.00) but not the other predictors we tested.

Of note, 1 transmasculine person who did not have sex with either cisgender men or transgender women, but was sexually active in the past 5 years, also reported taking PrEP.

Familiarity With PrEP (Sample 1)
About 48% of HIV-negative respondents who had sex in 5 years before taking the survey were familiar with Truvada as PrEP (47.6%, CI: 38.4% to 57.0%; Table 3), with 58% of transmasculine respondents and 35% of transfeminine reporting that they are familiar with PrEP (Table 3). In the adjusted multivariate logistic regression analysis (Table 4), transfeminine respondents were less likely than transmasculine respondents to be familiar with PrEP (OR: 0.3, CI: 0.1 to 0.8); respondents who did not meet recommendations for HIV testing were less likely to be familiar with PrEP than those who did meet HIV testing recommendations (OR: 0.3, CI: 0.1 to 0.9); and respondents whose highest education level was high school or less were less likely to be familiar with PrEP than those who have higher education levels (OR: 0.3, CI: 0.1 to 0.9).

Attitudes Toward PrEP (Sample 1)
Table 3 also shows that among respondents who were familiar with PrEP, most (72.0%, CI: 58.9% to 82.1%) reported favorable attitudes toward PrEP. Multiple logistic regression analysis (Table 4) showed that respondents who did not meet recommendations for HIV testing were less likely to report favorable attitudes toward PrEP than their counterparts (OR: 0.2, CI: 0.0 to 0.9).

DISCUSSION
To the best of our knowledge, this is the first study of HIV testing and PrEP use in a nationally representative sample of HIV-negative sexually active transgender people in the United States. Almost a quarter of transgender people at risk for sexual HIV acquisition due to sex with cisgender men and/or transgender women in the 5 years before the study had never been tested for HIV and 54% did not meet CDC recommendations for HIV testing once per year or more. That people of color and those who reported looking online for LGBT and/or transgender health information were more likely to meet CDC guidelines may reflect the success of HIV testing outreach programs that prioritize people at higher risk for acquiring HIV, focusing on those who are vulnerable to structural marginalization. This is consistent with studies that have found that transgender women and men of color, and black cisgender gay and bisexual men, were more likely than their white counterparts to report ever testing for HIV. These data also show that using LGBT sources for health information online is associated with adherence to testing recommendations. Being at risk for HIV acquisition likely drives both HIV testing rates and PrEP use.
uptake, and HIV testing may itself raise awareness of PrEP through posttest counseling.29

Awareness of PrEP was relatively low overall (48%) and was higher among transmasculine respondents than transfeminine. This is concerning, especially among a sexually active probability sample of transgender people, given the particularly high rates of HIV among transgender women. Very few transgender people reported currently taking PrEP (3%). Those who reported higher levels of nonaffirmation of their gender identity were less likely to use PrEP. This finding corroborates other studies that have found gender affirmation to be an important factor in the HIV prevention and treatment continua for transgender people,22,30 as well as reinforces the need for gender-affirming PrEP services for transgender people at risk of HIV acquisition.21 Ongoing public health efforts are needed to increase awareness and uptake of PrEP for transgender adults in the United States.

The availability of a nationally representative sample of transgender people is a unique strength of this study. Still some limitations are noteworthy. This was a cross-sectional study, which precludes clear determination of causality. Limitations due to the small sample size include that we categorized our sample into people of color vs. white individuals, which obscures within-group differences between people of color and creates a false dichotomy. Similarly, the low prevalence of PrEP use limited our ability to conduct multivariate analysis predicting PrEP use. Larger studies will be needed to explore nuanced differences among subgroups of transgender individuals. Regarding the risk for HIV, we used our measure of a 5-year history of sexual activity. The CDC guidelines recommend HIV testing at least once per year for people at high risk, but there are no specific HIV testing guidelines for transgender people, despite being identified as a key population at disproportionate risk for HIV.

Future directions include the need for clarified CDC guidelines for transgender people and the need to continue to prioritize outreach, education, and HIV prevention services and interventions for transgender people, who continue to be at elevated risk for HIV acquisition.31

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**TABLE 4. Predictors of HIV Testing, Familiarity With PrEP, and Attitudes Toward PrEP Among Transgender Individuals at Risk for HIV: the US National Probability Sample**

|                        | Met CDC Recommended HIV Testing Frequency† (N = 111) | Familiar With PrEP vs. Not (N = 188) | Favorable Attitudes Toward PrEP vs. Not§ (N = 88) |
|------------------------|-----------------------------------------------------|-------------------------------------|-----------------------------------------------|
|                        | OR (95% CI)                                          | OR (95% CI)                          | OR (95% CI)                                   |
| Sex assigned at birth  |                                                     |                                     |                                               |
| (ref: transmasculine/female at birth) |                                                     |                                     |                                               |
| Transfeminine/male at birth | 1.5 (0.4 to 5.7)                                     | 0.3 (0.1 to 0.8)*                    | 1.7 (0.4 to 7.7)                              |
| Age (continuous)       | 1.0 (1.0 to 1.1)                                     | 1.0 (1.0 to 1.0)                     | 1.0 (0.9 to 1.1)                              |
| Race/ethnicity (ref: white) |                                                     |                                     |                                               |
| POC                    | 8.2 (2.3 to 28.8)†                                   | 0.6 (0.2 to 1.6)                     | 0.8 (0.2 to 3.5)                              |
| Education (ref: more than high school) |                                                     |                                     |                                               |
| High school or less    | 0.2 (0.1 to 0.6)†                                    | 0.4 (0.1 to 0.9)*                    | 4.1 (0.8 to 20.7)                             |
| Urbanicity (ref: urban) |                                                     |                                     |                                               |
| Nonurban               | 0.6 (0.1 to 2.4)                                     | 0.8 (0.2 to 2.6)                     | 0.5 (0.1 to 2.5)                              |
| Poverty (ref: not in poverty) |                                                     |                                     |                                               |
| In poverty             | 1.0 (0.3 to 3.8)                                     | 0.9 (0.3 to 2.6)                     | 2.8 (0.5 to 15.2)                             |
| Tested for HIV, CDC standards (ref: yes) | N/A                                                 | 0.3 (0.1 to 0.9)*                    | 0.2 (0.0 to 0.9)*                             |
| Worried about getting HIV (ref: never) |                                                     |                                     |                                               |
| Sometimes or more      | 3.2 (0.9 to 10.6)                                   | 2.0 (0.8 to 5.4)                     | 0.4 (0.1 to 1.8)                              |
| Familiar with PrEP (ref: familiar) |                                                     |                                     |                                               |
| Not familiar           | 0.3 (0.1 to 1.2)                                    | N/A                                 |                                               |
| Looked online for LGBT/trans health info (ref: yes) |                                                     |                                     |                                               |
| No                     | 0.2 (0.1 to 0.6)†                                    | 0.6 (0.2 to 1.5)                     | 0.9 (0.2 to 3.6)                              |
| Nonaffirmation of gender identity (continuous) | 1.3 (0.7 to 2.4)                                     | 0.8 (0.5 to 1.2)                     | 0.8 (0.5 to 1.3)                              |

*P < 0.05.
†P < 0.01.
‡Among individuals who are HIV-negative and sexually active with cisgender men and/or transgender women in the past 5 years (N = 112).
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