



## Demographic characteristics associated with the use of HIV pre-exposure prophylaxis (PrEP) in an urban, community health center

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### ABSTRACT

Individuals who are at high risk of contracting HIV should have equitable access to preventive measures, such as pre-exposure prophylaxis (PrEP). We conducted a retrospective data extract from the electronic medical records of federally-qualified health centers in New York City from 2016 to 2018. Descriptive statistics are presented, stratified by those who have been prescribed PrEP and those who have not. We created a variable called “ever-female” which includes individuals assigned female at birth or who have ever identified as female. A chi-square test was performed to determine the statistical significance between variables as  $p < .05$ . A total of 9659 patients met inclusion criteria for the study. Patients who were prescribed PrEP were significantly associated with being white and never-female, with 38.2% of those prescribed PrEP identifying as white and 83.8% of those prescribed PrEP categorized as never-female. Patients of trans experience were 9.6% of the PrEP cohort and 1.5% of the never PrEP cohort ( $p < .001$ ). Patients identifying as Black/African American made up 19.8% of patients prescribed PrEP and 49.8% of those never prescribed PrEP ( $p < .001$ ). Patients with the lowest reported income composed 48.4% of those prescribed PrEP compared to 69.3% of patients who were never prescribed PrEP ( $p < .001$ ). These findings indicate that key demographic categories may not be accessing PrEP as much as would be expected for their level of risk. Barriers to access of PrEP for women and other at-risk, under-represented populations should be further studied.

### 1. Introduction

Since the beginning of the HIV/AIDS epidemic, there have been significant biomedical advances, namely the use of anti-retroviral medications, to both prevent and treat HIV infection (Baeten et al., 2013; Coates, 2013; Haaland et al., 2013; Ogbuagu and Bruce, 2014). In spite of these advances, disparities continue to define the populations most affected by the epidemic and inequitable access to healthcare, stigma, discrimination, and the social determinants of health contribute to these disparities (Beer et al., 2016; Buchacz et al., 2013; Earnshaw et al., 2013; Muthulingam et al., 2013). Key populations, specifically men who have sex with men (MSM), Black/African Americans, adolescents/young adults, sex workers, people who inject drugs, and people of trans experience are all at a higher risk of acquiring HIV (Dean et al., 2005; WHO, n.d.-a).

There currently is no way to reverse HIV infection, but it is treatable, manageable, and preventable (WHO, n.d.-b; Del Rio, 2014). In 2012, the U.S. Food and Drug Administration (FDA) approved a biomedical prevention method, the daily oral pill known as pre-exposure

prophylaxis or PrEP (Chan, 2012; Huang, 2018). Results from clinical research trials indicate that PrEP is safe to be used in a diversity of populations, including heterosexual men and women (Thigpen et al., 2012; Baeten et al., 2012) MSM, (Grant et al., 2010), transgender women (Grant et al., 2010), and people who inject drugs (PWID) (Choopanya et al., 2013). While PrEP has also been shown to effectively reduce the rate of HIV infection in randomized controlled trials (Thigpen et al., 2012; Baeten et al., 2012; Grant et al., 2010), adherence to the pill regimen is essential to therapeutic efficacy (Van Damme et al., 2012; Centers for Disease Control and Prevention, 2018). Based on the available evidence and mathematical models, the impact of HIV risk reduction efficacy of PrEP is estimated to be 99% for perfect, daily use and declines to 96% for 4 weekly doses and down to 76% for 2 doses per week (Centers for Disease Control and Prevention, 2018; Abbas et al., 2013).

PrEP has unique benefits, including dual protection from sex or injection risk of HIV; discretion; and the ability to use PrEP for individual protection without having to consult a sexual partner (Calabrese et al., 2017). PrEP is recommended as one option in a suite

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of HIV prevention services (WHO, n.d.-c; Best Actions, n.d.). In spite of these advantages, estimates that include 80% of PrEP prescriptions put the cumulative number of people who have started PrEP from 2012 to the end of 2017 at 140,000 in the U.S. (Siegler et al., 2018), even while over 1.2 million people are indicated as being at high risk of acquiring HIV infection (<https://www.cdc.gov/mmwr/preview/mmwrhtml/mm6446a4.htm>, 2015).

While there is reliable evidence regarding the efficacy, safety, and benefits of PrEP use, there is little data that describes PrEP by those demographic categories that are most impacted by HIV infection and preliminary data points to lower PrEP uptake among vulnerable populations (Calabrese et al., 2017; [http://www.natap.org/2016/HIV/062216\\_02.htm](http://www.natap.org/2016/HIV/062216_02.htm), n.d.). The primary objective of this study is to describe the demographic characteristics of patients clinically indicated to be at high-risk of HIV infection in a setting dedicated to the underserved. Within this population, the characteristics of those who have been prescribed PrEP will be compared with those who have never been prescribed PrEP to better understand possible disparities that exist and how to address them.

## 2. Methods

### 2.1. Participants and procedures

This is a retrospective, descriptive cohort study of electronic medical record (EMR) data at large network of urban, federally qualified health centers (FQHC), Community Healthcare Network (CHN). As an FQHC, CHN receives federal funding that makes it financially equipped to provide quality care to some of the most vulnerable populations, such as low-income and under and uninsured populations. The study was determined to be exempt from review by CHN's institutional review board.

Data was extracted from CHN's EMR. As a primary care provider, all of CHN's clinicians are trained in the prescription of PrEP and PrEP navigation is available to all CHN patients. Patients were eligible for inclusion in the study if they had a clinical visit between January 1, 2016 and May 31, 2018 and had clinical indicators of being at higher risk for HIV infection but were HIV-negative. We used the New York State Department of Health (NYS DOH) AIDS Institute guidelines to inform our choice of inclusion criteria where possible. We searched for patients who had a positive lab test or ICD-10 diagnosis of syphilis, chlamydia, or gonorrhea in the 12 months prior to and including the date of their clinical visit. In addition, we included those who identified themselves as sex workers within 12 months prior to and including the date of their clinic visit, individuals who had been previously prescribed two or more courses of PEP and did not have a sexual assault ICD code in the same visit as the PEP prescription, and individuals who answered "yes" to the question: "Are you currently injecting drugs?" within the 12 months prior to and including the date of their clinic visit. Our providers have been trained to use Z20.2 and Z20.6 as the primary ICD-10 codes to indicate need for PrEP prescription according to NYS DOH guidelines but we also have informal knowledge that our clinicians also use Z-codes to indicate that their patients have "high-risk sexual behavior". In order to capture this assessment, we also searched for patients who had been diagnosed with the following ICD-10 codes that indicate "high-risk sexual behavior" or exposure to STIs: Z20.2, Z20.6, Z72.5, Z72.51, Z72.52, and Z72.53 in the 12 months prior to and including the date of their clinic visit.

### 2.2. Measures

Demographic information for patients who met the inclusion criteria were also extracted, which included administrative sex, gender identity, language, race/ethnicity, age group, and income level. All of these demographic measures are collected at patient registration and are patient reported. As an FQHC, CHN does not turn patients away for

any reason, including the ability to pay or insurance status. For those without insurance, CHN relies on a sliding fee scale to determine the amount the patient will pay out of pocket, which is based on verifiable documentation of income when available or self-report. To encompass all individuals who had administrative sex marked as female or who have ever identified as female in the medical record, we created an additional variable called "ever-female". Eligible patients for the study will be categorized into two groups: those who have been prescribed PrEP and those who have not. In the absence of an ICD-10 code for PrEP, patients who were HIV-negative and prescribed Truvada (the brand name of the prescription medicine emtricitabine/tenofovir used for HIV pre-exposure prophylaxis) only were identified as patients prescribed PrEP.

### 2.3. Statistical analysis

We describe the distribution of all the variables of interest for the total sample and then separately for those patients who had been prescribed PrEP and those who had not been prescribed PrEP. We conducted chi-square tests to assess statistical significance when examining association of a categorical variable with PrEP prescription. All statistical tests were 2-sided with a p-value < .05 for rejection of the null hypothesis. All analyses were conducted using R statistical environment (version 3.4.0).

## 3. Results

A total of 9659 patients met inclusion criteria for the study. 1866 patients at CHN had been prescribed PrEP while 7793 patients who are at high risk for HIV had not been prescribed PrEP. The chi-square tests were statistically significant between each of the demographic categories we analyzed and PrEP prescription and are presented in [Table 1](#).

There were 5164 patients who had their administrative sex marked as female in the entire sample of patients clinically indicated for PrEP. Of these patients, 194 or 3.8% received a prescription for PrEP compared to 37.2% of those whose administrative sex was marked male. Of patients characterized as ever-female (n = 5358), 5.7% received a prescription for PrEP compared to 36.3% of those who were categorized as never-female. For patients of trans experience (n = 297), more than half (60.3%) had been prescribed PrEP. There were 4098 participants in the total sample who identified as female and 249 (6.1%) were prescribed PrEP compared with 43.7% of those identified as male, 37.5% of those who identified as genderqueer or other, and 14.0% of those whose gender identity was unknown.

There were 4248 Black/African American individuals who met the inclusion criteria for this study and 369 (8.7%) were prescribed PrEP compared with 30.6% and 43.1% for those who identified as white and Asian respectively. Among those who identified as Hispanic/Latinx (n = 3828) 21.7% were prescribed PrEP compared with 17.7% of those who did not identify as Hispanic/Latinx (n = 5831).

The income of participants was captured as percent of the federal poverty level (FPL). As reported income increased in our sample, so did the proportion of individuals prescribed PrEP. At the lowest income level, 14.3% of patients were prescribed PrEP compared with 41.7% of those in the highest income level.

The age group with the largest proportion of PrEP prescriptions (32.7%) was the age group 36–45 years old (n = 1231). The age groups with the lowest proportions of PrEP prescriptions were the youngest age groups, with 0.6% of those under 18 and 7.0% of those between 18 and 25 receiving PrEP prescriptions.

## 4. Discussion

Condoms, safer sex practices, and the introduction of PrEP have not been completely effective in the prevention of new cases of HIV. New cases of HIV are diagnosed daily, which points to barriers to care and

**Table 1**  
Socio-demographic characteristics of patients clinically indicated for PrEP by PrEP prescription in a network of FQHCs in New York City, 2016–2018.

Characteristics	Total sample number (%)	PrEP (%)	No PrEP (%)	p-Value
Total	9659	1866 (19.3%)	7793 (80.7%)	
Administrative sex				< .001
Female	5164 (53.5%)	194 (10.4%)	4970 (63.8%)	
Male	4495 (46.5%)	1672 (89.6%)	2823 (36.2%)	
Trans-identified				< .001
No	9362 (96.9%)	1687 (90.4%)	7675 (98.5%)	
Yes	297 (3.1%)	179 (9.6%)	118 (1.5%)	
Gender identity				< .001
Female	4098 (42.4%)	249 (13.3%)	3849 (49.4%)	
Genderqueer/other	16 (0.2%)	6 (0.3%)	10 (0.1%)	
Male	2812 (29.1%)	1229 (65.9%)	1583 (20.3%)	
Unknown	2733 (28.3%)	382 (20.5%)	2351 (30.2%)	
Ever-female				< .001
Yes	5358 (55.5%)	303 (16.2%)	5055 (64.9%)	
No	4301 (44.5%)	1563 (83.8%)	2738 (35.1%)	
Ethnicity				< .001
Hispanic/Latinx	3828 (39.6%)	832 (44.6%)	2996 (38.4%)	
Not Hispanic/Latinx	5831 (60.4%)	1034 (55.4%)	4797 (61.6%)	
Race				< .001
American Indian/Alaska Native	75 (0.8%)	18 (1.0%)	57 (0.7%)	
Asian	297 (3.1%)	128 (6.9%)	169 (2.2%)	
Black/African American	4248 (44.0%)	369 (19.8%)	3879 (49.8%)	
More than one race	90 (0.9%)	22 (1.2%)	68 (0.9%)	
Native Hawaiian	6 (0.1%)	0 (0%)	6 (0.1%)	
Other Pacific Islander	112 (1.2%)	19 (1.0%)	93 (1.2%)	
Unreported	3073 (31.8%)	597 (32.0%)	2476 (31.8%)	
White	1758 (18.2%)	713 (38.2%)	1045 (13.4%)	
Language				< .001
English	8465 (87.6%)	1510 (80.9%)	6955 (89.2%)	
Spanish	1040 (10.8%)	328 (17.6%)	712 (9.1%)	
Other	154 (1.6%)	28 (1.5%)	126 (1.6%)	
Age group				< .001
Under 18 years old	172 (1.8%)	1 (0.1%)	171 (2.2%)	
18–25 years old	3780 (39.1%)	263 (14.1%)	3517 (45.1%)	
26–35 years old	3640 (37.7%)	1035 (55.5%)	2605 (33.4%)	
36–45 years old	1231 (12.7%)	403 (21.6%)	828 (10.6%)	
46–55 years old	500 (5.2%)	127 (6.8%)	373 (4.8%)	
56–64 years old	229 (2.4%)	29 (1.6%)	200 (2.6%)	
65+ years old	107 (1.1%)	8 (0.4%)	99 (1.3%)	
Poverty Level (% FPL)				< .001
100 and below	6306 (65.3%)	904 (48.4%)	5402 (69.3%)	
101–150	1042 (10.8%)	230 (12.3%)	812 (10.4%)	
151–200	637 (6.6%)	150 (8.0%)	487 (6.2%)	
201–250	358 (3.7%)	113 (6.1%)	245 (3.1%)	
Over 250	933 (9.7%)	389 (20.8%)	544 (7.0%)	
Unknown	383 (4.0%)	80 (4.3%)	303 (3.9%)	

uptake of preventive methods such as stigma, provider bias, and lack of knowledge (*Henry J Kais Fam Found*, 2018). In this retrospective analysis of EMR data from a large network of community-based health centers in New York City, we have found evidence that many key populations at increased risk for HIV infection are not being adequately reached with an important biomedical HIV prevention method. Prescription for PrEP is associated in this study with being white, never-female, and higher income, which is in line with previous, preliminary data ([http://www.natap.org/2016/HIV/062216\\_02.htm](http://www.natap.org/2016/HIV/062216_02.htm), n.d.). This finding is especially incongruent with the population CHN serves, which is predominantly composed of individuals of color, women, and low-income populations.

Reasons for these findings might include clinician bias (*Calabrese et al.*, 2014), strong social networks among never-females, such as MSM, who have a long history of community leadership in response to the HIV epidemic and as advocates for advances in HIV care (*Trapence et al.*, 2012), and the focus of advertising and grant funds and programs that have been aimed at reaching never-females, such as MSM, as well as trans-identified individuals (*Rebchook et al.*, 2017), both of whom are key target population in order to achieve the goals of Governor Cuomo's three-point plan to End the Epidemic (EtE). Our findings on income were somewhat surprising, given the extensive array of PrEP

patient assistance programs funded by the Truvada manufacturer at little or no cost to the patient, which alleviate the financial burden of PrEP for patients who need it, but requires a complex navigation process which might further impact barriers based on knowledge.

The primary strength of this study is the analysis of demographic disparities in PrEP prescription. There are also several limitations to this study. There were missing data in gender identity and race. For gender identity, we believe this to be the result of better collection methods beginning in 2017 as well as the efforts of grant-funded assistance and support programs which are available to patients after being prescribed PrEP. For race, the majority of participants who identified with the unknown or refused to report racial category identify as Hispanic or Latinx and do not readily identify with any of the racial categories. Some individuals who do not identify as Hispanic or Latinx have also chosen unknown. Although there are unknowns present in our data, this study's scope is descriptive, and the missing data is reflective of the reality of the difficulty in capturing personal identification in a discrete, categorical way.

There is the possibility of misclassification error for those who identify as trans, due to the timing of their transition compared with when data was collected. There is further possibility of misclassification error with the outcome variable as it is possible that patients in our

sample have received PrEP prescription elsewhere.

A final limitation of this study is the use of ICD-10 codes for inclusion criteria in the study. We attempted to align our inclusion criteria as closely as possible with the NYS DOH AIDS Institute guidelines and in order to capture “high risk behavior” we used several ICD codes that have limitations. (Quan et al., 2008) Providers have the discretion to determine what risky sexual behavior is and therefore, patients with these codes may be subjected to provider bias. In spite of these limitations, it is currently the best way we have to summarize clinician assessment of patient risk at the time of their visit.

Increased knowledge of and access to PrEP is critical to ensure all individuals at risk for HIV have the full range of preventive options. In order to end the HIV epidemic in alignment with NY State's goals to EtE and the nation's goals for Healthy People 2020, it is especially important to understand how PrEP messaging is being perceived by key populations who have the greatest need for HIV prevention, both to avoid disparities in HIV prevention and to improve HIV incidence outcomes. Individuals who are at risk for contracting HIV should be provided with education and the option of accessing all possible HIV prevention methods that they choose to use. In our study, 9649 patients met inclusion criteria. Of those patients, only 19.3% or 1866 had been prescribed PrEP by a CHN clinician, which leaves over three-quarters of patients in this sample without a verifiable PrEP prescription. Our study shows that there are gaps in access to key populations at risk for HIV infection and future research should focus on why those gaps exist as well as to determine what is needed to effectively engage those populations in appropriate HIV preventive care.

## Declaration of Competing Interest

The authors have no conflict of interests to declare.

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