Predictors of PrEP Retention and Attrition in an Urban Publicly Funded Safety-net Specialty Clinic

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Abstract

Pre-exposure prophylaxis (PrEP) is an effective tool for human immunodeficiency virus (HIV) prevention. The purpose of this study is to identify correlates of PrEP retention using patient data from an urban, publicly funded safety-net clinic in Washington, DC. Cox proportional hazards regression, logistical regression, and survival curves were used to assess the association of age, gender, race/ethnicity, insurance, number of partners, and sexually transmitted infection (STI) diagnosis at PrEP initiation with time on PrEP. From August 2016-December 2020, 1,126 people were prescribed PrEP - patients were mostly Black (44.8%) or Latinx (30.4%) and identified as cisgender men (84.6%). Half had no insurance (49.1%), with the remaining patients reporting private (28.9%) or public (21.5%) insurance. Age at PrEP prescription ranged from 15 to 66 with 80% being 20 to 39 years. For the 87.7% ($n = 987$) of patients who discontinued PrEP, mean PrEP time was 158 days and median was 28 days. The highest rates of discontinuation were observed within the first month with 44.3% discontinuing by day 30, 52.3% by 3 months, and 73.2% by 1 year. Cisgender women, transgender persons, and those younger than 30 years were more likely to discontinue PrEP. Latinx and patients with less than 3 male partners in the last 90 days were less likely to discontinue PrEP. We demonstrated a high level of PrEP uptake among populations disproportionally affected by HIV Future analyses are needed to examine ways of reducing barriers to PrEP initiation and improving PrEP adherence.

Keywords

HIV/AIDS; HIV Prevention; PrEP; Men who have sex with men (MSM); STI Clinic

Introduction

HIV continues to impact both morbidity and mortality in the US and the District of Columbia (DC) after more than forty years since the start of the HIV epidemic. More

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than 1 out of every 75 DC residents (1.7%) are living with HIV and more than two hundred new infections occur annually [1]. According to the US Centers for Disease Control and Prevention (CDC) 2020 HIV Surveillance Report, DC had the highest rate of new HIV infections (32.3 per 100,000) and HIV prevalence (2,260.4 per 100,000) among those ≥ 13 years in the US [2]. New and existing HIV infections disproportionately impact racial and sexual minorities, both in DC and nationwide [2, 3]. Of the 12,161 current DC residents living with HIV, 85% are people of color, with a majority being Black (71.4%) or Latinx (8.2%) [1]. Additionally, 57% of 2020 new infections in DC were among men that have sex with men (MSM) and 40% were among those less than 30 years old [1]. DC and neighboring counties are identified as priority jurisdictions in national Ending the HIV Epidemic plans [4].

Pre-exposure prophylaxis for HIV (PrEP) has been FDA approved since 2012 to reduce the risk of acquiring HIV infection [5]. PrEP is both safe and efficacious in significantly reducing the risk of HIV acquisition when taken consistently [6, 7]. However, there continues to be a significant need for expanded PrEP provision, particularly for Black and Latinx populations, MSM, and cis-gender women both nationally and within DC [8–11]. CDC guidelines recommend discussing PrEP with all sexually active persons [12]. Nationally, it is estimated that if the CDC guidelines are followed and 40% of MSM with PrEP indications take PrEP, new HIV infections could be reduced by 33% [10]. Barriers to PrEP provision are multifaceted but are known to include concerns about side effects, provider-perceived eligibility, lack of provider knowledge and experience, and cost-barriers [13–15].

Publicly run- and funded or municipal sexually transmitted infection (STI) clinics provide varied sexual health services at low or reduced cost to individuals who are often un- or underinsured [16], younger, and members of racial or sexual minorities [17, 18] – groups disproportionately affected by HIV incidence. As of 2017, there are 2,668 STI clinics run by state or local health departments in the United States [19]. Given the association between STIs and HIV [20, 21], STI clinics have been identified as one of the key venues for expansion of PrEP provision services in the US [22], however despite serving a critical role in diagnosing and treating STIs, municipal STI clinics have been slow to deliver HIV pharmaco-prevention services [23].

Limited data exists on the experience of PrEP provision within municipal STI clinics. CDC guidelines for quality clinical services provide a strong recommendation that specialty STI clinics should provide PrEP for HIV prevention [24]. Demonstration projects have shown municipal STI clinics can successfully initiate patients on PrEP [25, 26], however, data on PrEP retention in this setting is limited, with ranges of persistence at six months from 32–60% [27–29]. No studies have investigated PrEP persistence at a municipal STI clinic with universal PrEP screening and direct, on-site, free PrEP initiation and existing PrEP studies have described the need for more long-term retention studies [30].

In this paper, we outline nearly four years of PrEP experience at the DC Health and Wellness Center (DCHWC), an urban publicly-funded safety-net specialty clinic. The DCHWC serves racial and sexual minorities and focuses on diagnosing, treating, and preventing HIV, STIs,

TB, and hepatitis. Overall, the DCHWC served 3,563 individuals for STI and HIV services in 2023, with 57% and 13% being Black or Latinx respectively. This study will describe PrEP provision in a municipal STI clinic and the population receiving PrEP. The purpose of this analysis is to examine demographic factors associated with length of PrEP use and outline predictors for PrEP retention in order to optimize clinical operations and prioritize resources in similar settings.

Methods

Protocols

A PrEP protocol was developed in early 2016 using CDC clinical practice guidelines [12]. During the initial formulation of the program in late 2016, patients either made appointments directly with the PrEP navigator or were referred to the navigator via a routine STI screening visit. As part of the PrEP intake process, the PrEP navigator collected demographics, self-reported STI history, behaviors, supportive service needs, and financial/insurance concerns through a detailed interview recorded in REDCap (Research Electronic Data Capture), a secure, web-based tool for collecting data [31]. The PrEP navigator connected patients to supportive services such as mental health and substance use services and helped with applications to assistance programs or health insurance to help cover costs. Patients also met with a medical provider to address any specific questions or concerns about PrEP, take a comprehensive sexual history, conduct chlamydia and gonorrhea screening based on site of exposure, get a test for syphilis, and get both a rapid 3rd generation HIV-1/HIV-2 antibody test and a 4th generation HIV-1/HIV-2 antibody/antigen test. If the rapid HIV test was negative, PrEP eligible patients received a 7-day starter pack of PrEP (30-day starter pack initially given August-December 2016) and made an appointment to return in a week to assess medication compliance and tolerance, desirability to continue, and to receive a 3-month PrEP prescription. PrEP patients were instructed to return to DCHWC quarterly for a follow-up appointment to assess continuing PrEP, discuss sexual practice changes and supportive service needs, screen for HIV/STIs, and monitor liver and kidney function. Between August 2016 and September 2018 the clinic focused screening efforts on populations recommended in the initial 2014 CDC PrEP guidelines, namely MSM, transgender individuals, and those in HIV sero-discordant relationships, but would start anyone on PrEP that wanted it whether they met the official criteria for PrEP use or not [12]. Beginning in October 2018, the clinic began screening, discussing, and offering PrEP to all individuals who sought clinical care at the clinic, referenced as universal PrEP screening.

Data Collection

For this analysis, data was retrospectively extracted from eClinical Works (eCW), the electronic medical record system used at DCHWC. eCW data included patient reported risk factors, sexual practices, labs, appointment dates, and concomitant medications. Information fields that were missing from eCW extraction were supplemented with REDCap interview data. Patients were included in the cohort if they met the following inclusion criteria: HIV negative at PrEP initiation; started PrEP at the DCHWC between August 1, 2016-December 31, 2020; and became an established PrEP client with the DCHWC; Exclusion criteria

were: a pre-existing HIV positive diagnosis as determined by eHARS (electronic HIV/AIDS Reporting System) matching and not being willing or able to be seen for follow up visits. Chart reviews were conducted to confirm prescription of PrEP, prescription date, time on PrEP, and reasons for stopping PrEP. In instances where patients started and discontinued PrEP more than once, the first PrEP use was used for this analysis.

Basic frequencies were calculated to describe the total PrEP population including demographics and risk factors. Time on PrEP was calculated with PrEP prescription date and discontinuation date through December 2021. If exact discontinue dates were not listed in the chart, discontinue dates were estimated using the last appointment date. Those with an initial PrEP visit that did not return were given a discontinue date of the day after the PrEP initiation appointment.

Statistical Analysis

Cox proportional hazards regression and survival curves were used to assess the association of the following demographics and risk factors and time (days) on PrEP: age (< 30 years, 30 years), race/ethnicity, current gender, insurance type (private, public, none), number of male partners in the 90 days prior to PrEP initiation (0–2, 3), and diagnosis of one or more bacterial STI(s) at PrEP prescription (chlamydia, gonorrhea, and syphilis). New syphilis cases and staging were confirmed via chart review. Condom use was excluded from the analysis as this question was not answered consistently. For STI(s) at time of PrEP prescription the closest result was taken within 30 days of PrEP initiation. Individuals that did not discontinue PrEP as of December 2021 were censored. Logistic regression models were run to measure the effect of the same factors on being on PrEP at least one month and to evaluate any changes in the patient population after universal screening was enacted in October 2018. All analyses were conducting using SAS software version 9.4 [32].

Results

From August 2016-December 2020, 1,126 people were prescribed PrEP at the DCHWC. The majority were Black (44.8%) or Latinx (30.4%) and identified as male (84.6%). Overall 83.2% of patients were MSM and 66.4% were MSM of color. Half of patients had no reported insurance (49.1%), with the remaining patients being on private (28.9%) or public (21.5%) insurance. Age at PrEP prescription ranged from 15 to 66 years old with a median age of 28, though more than 80% were between 20 and 39 years of age. For the 87.7% ($n =$ 987) of patients that discontinued PrEP by December 2021, mean PrEP time was 158.0 days, median was 28 days (range 1–1,450 days), and the highest rates of discontinuation were observed within the first month; with 44.3% discontinuing by day 30, 52.3% by 3 months, 61.7% by 6 months, and 73.2% by 1 year. Most patients had no STI diagnosed at PrEP initiation (70.0%). Of those with an STI diagnosed at PrEP initiation, 247 (21.9%) had one STI and 68 (6.0%) had two or more STIs (Table 1).

The reason for discontinuing PrEP was captured for 15.4% of those that discontinued ($n =$ 152), with the remaining being lost to follow-up. Gender, race/ethnicity, insurance status, and age group did not differ between individuals that gave reasons for discontinuing PrEP and those that did not (data not shown). The most common reasons for discontinuing

PrEP at the DCHWC among this sample were side effects (24.3%), switching to a new PrEP provider (13.8%), not being interested in PrEP (13.2%), insurance or prescription issues (11.8%), and relationship status changes, i.e. becoming monogamous, ending a relationship with a person living with HIV, etc. (11.2%) (Table 2). The most frequent side effects mentioned were gastrointestinal issues such as vomiting, diarrhea, and nausea. Four individuals that were started on PrEP seroconverted due to poor adherence, pandemic related access issues, a combination of unstable housing and bipolar disease, and in the final case, the patient likely had acute HIV when PrEP was started.

Patients identifying as female (HR: 1.9, 95% CI 1.5–2.4) or other (gender queer, transgender) (HR: 1.6, 95% CI 1.2–2.3) were more likely to discontinue PrEP than males. Latinx individuals were slightly less likely to discontinue PrEP than White individuals (HR: 0.77, 95% CI 0.62–0.95). Those younger than 30 years old were more likely to discontinue PrEP than those 30 years old (HR: 1.3, 95% CI 1.1–1.5). Patients with 3 male partners in the last 90 days were less likely to discontinue PrEP (HR: 0.79, 95% CI 0.68–0.92). Insurance status and having at least one STI diagnosed at PrEP initiation were not associated with PrEP discontinuation (Table 3). Survival curves were calculated and appear in Fig. 1.

Universal PrEP screening was used for 60.9% of the 1,126 patients. Patients that started PrEP after the initiation of universal PrEP screening at DCHWC were more likely to be female (OR: 2.0, 95% CI 1.2–3.2) than male and less likely to have 3 or more male partners in the last 90 days (OR: 0.66, 95% CI 0.50–0.86). Patients after universal screening were also more likely to have been diagnosed with at least one bacterial STI at PrEP prescription (OR: 1.4, 95% CI 1.1–1.9). Race/ethnicity, insurance, and age at prescription were not significantly different before and after universal screening (data not shown).

We explored predictors for staying on PrEP for at least one month given the high rate of PrEP discontinuation within the first month after initiation. Patients on PrEP for 1 month were more likely to be Latinx (OR: 2.3, 95% CI 1.5–3.5) than White, and had greater odds of being insured (OR: 1.5, 95% CI 1.1-2.0). Those on PrEP for 1 month were less likely to be both female (OR: 0.29, 95% CI 0.18–0.47) and younger than 30 years (OR: 0.62, 95% CI 0.47–0.82) (Table 4).

Discussion

This study examines the association of demographic factors with PrEP retention to better support those accessing PrEP and encourage this effective HIV prevention strategy. This study adds to the growing evidence that publicly-run and funded STI clinics can successfully provide PrEP to racial and sexual minorities disproportionately impacted by HIV and help bridge racial disparities present in PrEP provision [27–29]. This evaluation demonstrated a high level of PrEP uptake and initiation at a municipal STI clinic, in particular among populations disproportionally affected by HIV with historically lower PrEP uptake when compared with White MSM [9]. Enacting universal screening increased the number of women and transgender/other gender persons on PrEP at the clinic, but overall women, transgender persons, and individuals < 30 were more likely to discontinue PrEP. Additionally, we saw that Latinx patients were significantly less likely to discontinue PrEP

compared to White patients. This may be a result of White patients being able to establish another medical home more easily or already having a primary care physician to transfer PrEP care. Furthermore, continued engagement with PrEP within this clinical setting allows for comprehensive sexual health services including regular STI screenings, sexual health associated vaccinations, and connections to community organizations. However, much work remains in reducing barriers to successful PrEP uptake and decreasing the disparities in PrEP continuation among different groups.

Interestingly in our study we found that patients with   3 male partners in the past 90 days were less likely to discontinue PrEP but having an STI at baseline did not affect overall PrEP continuation. This may suggest that individual risk perception may be more related to partner number than recent STI diagnosis within our clinical population. The finding that having more sexual partners was associated with reduced risk of stopping PrEP was also observed in a Baltimore PrEP study with a similar population [33]. However, our findings differ from results of a mostly White population of PrEP patients in San Francisco that demonstrated lower retention for those with an STI at baseline [34]. Additional qualitative and quantitative research is needed to evaluate factors influencing PrEP retention.

Although only a small number of reasons for discontinuing PrEP were collected (Table 1) as most patients were lost to follow-up, the major reasons for discontinuing such as side effects and no longer being interested in PrEP were similar to findings from other studies that highlighted reduced need or low risk of infection and logistical issues as reasons for discontinuing [13, 35, 36]. While insurance / prescription issues were only cited by 11.8% of patients as a reason for discontinuation, persons without insurance were more than half as likely to discontinue PrEP at one month compared to those with insurance. This suggests that progress has been made in the ease of making PrEP accessible and affordable, especially at the DCHWC where the process has been streamlined, patients are provided 7-day starter packs, and navigators offer help with assistance programs. Patients could quickly get medication in hand during lapses in coverage, logistical issues, or a delay in assistance programs. Insurance is not necessary for receiving care at this STI clinic and ability to pay does not affect whether a patient will be seen by a provider, but this analysis showed that having insurance may facilitate longer adherence to PrEP. Assistance programs should have easy application processes and expand eligibility criteria to extend benefits to more people. However, with such a small proportion of individuals reporting reasons for discontinuing PrEP, we may be underestimating the influence of lack of insurance on PrEP discontinuation. Despite best efforts, four people became HIV positive after starting PrEP at the DCHWC. Additional work is needed to both identify those that seroconvert and prevent this from happening by promoting adherence, ensuring consistent access to healthcare, and linking to mental health services.

This study reinforced previous concerns regarding the importance of the first follow-up visit in terms of PrEP retention. Our patient population showed a 44% drop off before day 30, which is high compared to existing data regarding PrEP retention at other municipal STI clinics [29, 34] This could potentially be due to the novel provision method (free pills in-hand, universal screening / low barrier provision). It should also be considered that the DCHWC is a safety net provider that made it easy for anyone to start PrEP and worked

with patients to continue on PrEP at no or low cost – which may have included transferring their care based on insurance status or pre-established medical home and thus increasing the discontinuation rate found at our clinic.

When considering incremental retention past one month, discontinuation rates of 14% at 3 months, 31% at 6 months, and 52% at 12 months reflect similar trends at other publicly-funded and run STI clinics [29, 33]. The one-month time point is important for overall PrEP retention, therefore close follow-up in the first month post initiation may be essential to increasing PrEP adherence. Barriers or concerns could be addressed early to decrease the large drop-off seen within a month of initiation if a PrEP case manager were available to follow up with any patients that miss their 1 week or 3 month appointments. Automatic clinic reminders such as emails or text messages may also assist patients in returning to the clinic on time.

Our data supports previous studies identifying the need for additional outreach for younger patients, cis-gender women, and transgender/genderqueer populations who were less likely to remain on PrEP [33, 37–39]. The barriers to continued use/reasons for discontinuing PrEP for these individuals should be explored to identify best practices for retaining these patients in care. In addition, the clinic did not offer gender-affirming care for transgender clients and which may help with retention among this population. These groups may also benefit from additional targeted support throughout their PrEP use such as having PrEP included in regular OB/GYN visits or as an optional addition to hormonal therapy.

There are several limitations to this study. Risk factors and demographic data were self-reported, which may underestimate risk. Identification of STIs was limited to local labs performed by the DCHWC and did not include external data sources such as other state health departments in which the PrEP patients lived. The PrEP discontinuation date was an estimate based on chart reviews due to no access to pharmacy dispensation data, and assumptions were made that the patient took the medications as prescribed. Therefore, time on PrEP is an estimate based on the information available from the DCHWC records. Most patients were lost to follow-up, and we were only able to collect reasons for discontinuing PrEP from 15.4% of those that discontinued. As a result, the reasons for discontinuing may not be representative of the larger group.

HIV pre-exposure prophylaxis can be universally provided at low or no-cost to the patient in a low barrier, easily accessible, publicly funded, safety-net sexual health clinic. This model excelled at initiating and retaining MSM of color on PrEP but experienced less success with cis- and transgender women. Future analyses should continue to explore ways of reducing barriers to PrEP initiation, improving PrEP adherence, and evaluating reasons for PrEP discontinuation.

Acknowledgements

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(a) Overall

(b) Current Gender

(c) Race/Ethnicity

(d) Age at PrEP prescription
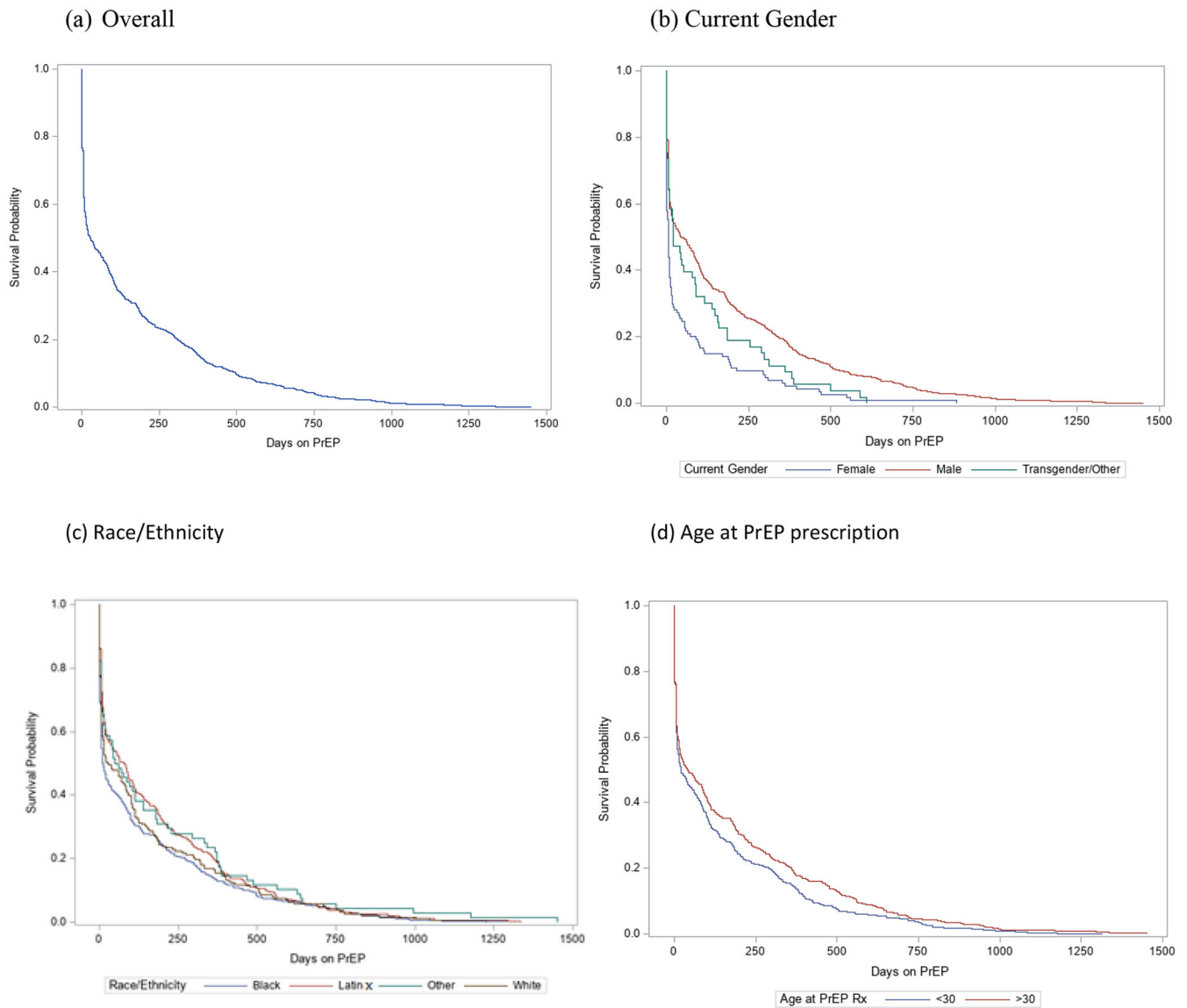
Fig. 1.
Kaplan-Meier survival plots for PrEP continuation by demographic characteristics,
Washington DC, 2016–2020

Table 1

STI results at PrEP initiation at the DC Health and Wellness Center, 2016–2020 ($n = 1,126$)

STI	N	%
None	788	70.0
Syphilis	75	6.7
Gonorrhea	87	7.7
Chlamydia	85	7.5
Gon/Syph	14	1.2
Syph/CT	13	1.2
Gon/CT	32	2.8
All 3	9	0.8
Missing	23	2.0
Total	1,126	100.0

Table 2

Reasons for discontinuing PrEP at the DC Health and Wellness Center, 2016–2020 ($n = 152$)

Reason for discontinuation of PrEP	N	%
Side effects	37	24.3
Changed PrEP provider	21	13.8
No longer interested	20	13.2
Issues with insurance/prescription	18	11.8
Relationship status change	17	11.2
Moved location	14	9.2
Low risk perception	13	8.6
Other medical/personal problems	8	5.3
Seroconverted HIV+	4	2.6
Total	152	100.0

Table 3

Demographics of PrEP patients and adjusted Hazard Ratios for discontinuing PrEP, Washington, DC 2016–2020. ($N = 1,126$)

Characteristic	n (%)	aHR	95% CI
Race/Ethnicity			
Black	503 (44.7)	0.89	0.73–1.1
Latinx	341 (30.3)	0.77	0.62–0.95
White	201 (17.8)	ref	-
Other[a]	77 (6.8)	0.78	0.58–1.1
Unknown	4 (0.4)	-	-
Current Gender			
Male	952 (84.6)	ref	-
Female	116 (10.3)	1.9	1.5–2.4
Transgender/Other[b]	58 (5.1)	1.6	1.2–2.3
Age (years)			
15–19	55 (4.9)		
20–24	264 (23.4)		
25–29	338 (30.0)		
30–39	306 (27.2)		
40–19	108 (9.6)		
50–59	42 (3.7)		
60	13 (1.2)		
Age Category (years)			
< 30	657 (58.4)	1.3	1.1–1.5
30	469 (41.6)	ref	-
Insurance status			
Private	325 (28.9)	ref	-
Public	242 (21.5)	1.0	0.84–1.3
None	553 (49.1)	1.1	0.94–1.3
Unknown	6 (0.5)	-	-
1 STI(s) diagnosed at PrEP initiation			
No	788 (70.0)	ref	-
Yes	348 (28.0)	1.1	0.93–1.3
Unknown	23 (2.0)	-	-
# of Male partners in 90 days prior to PrEP initiation			
0–2	467 (41.5)	ref	-
3	482 (42.8)	0.79	0.68–0.92
Unknown	177 (15.7)	-	-

[a] American Indian or Alaska Native, Asian, Native Hawaiian Pacific Islander, Middle Eastern, Other

[b] Gender queer, Transgender, Non-binary, Other

Table 4

Demographics of PrEP patients and adjusted Odds Ratios for being on PrEP for at least 1 month, Washington, DC 2016–2020. ($N = 1,126$)

Characteristic	PrEP ≥ 1 mon $n = 628$	PrEP < 1 mon $n = 498$	aOR	95% CI
	n (%)	n (%)		
Race/Ethnicity				
Black	248 (39.5)	255 (51.2)	1.3	0.86–1.8
Latinx	222 (35.5)	119 (23.9)	2.3	1.5–3.5
White	106 (16.8)	95 (19.1)	ref	-
Other[a]	49 (7.8)	28 (5.6)	1.7	0.96–3.2
Unknown	3 (0.50)	1 (0.20)	-	-
Current Gender				
Male	564 (89.8)	388 (77.9)	ref	-
Female	34 (5.4)	82 (16.5)	0.29	0.18–0.47
Transgender/Other[b]	30 (4.8)	28 (6.6)	0.51	0.28–0.94
Age (years)				
15–19	23 (3.7)	32 (6.4)		
20–24	136 (21.7)	128 (25.7)		
25–29	188 (29.9)	150 (30.1)		
30–39	189 (30.1)	117 (23.5)		
40–19	66 (10.5)	42 (8.5)		
50–59	18 (2.9)	24 (4.8)		
60	8 (1.2)	5 (1.0)		
Age Category (years)				
< 30	347 (55.2)	310 (62.2)	0.62	0.47–0.82
30	281 (44.8)	188 (37.8)	ref	-
Insurance status				
Yes	330 (52.6)	237 (47.6)	1.5	1.1–2.0
No	298 (47.4)	255 (51.2)	ref	-
Unknown	0 (–)	6 (1.2)	-	-
1 STI(s) diagnosed at PrEP initiation				
No	444 (70.7)	344 (69.1)	ref	-

Characteristic	PrEP ≥ 1 mon *n* = 628	PrEP < 1 mon *n* = 498	aOR	95% CI
	n (%)	*n* (%)		
Yes	173 (27.5)	142 (28.5)	-	-
Unknown	11 (1.8)	12 (2.4)	-	-
# of Male partners in 90 days prior to PrEP initiation				
0–2	242 (38.5)	225 (45.2)	ref	-
3	297 (47.3)	185 (37.1)	1.4	1.1–1.9
Unknown	89 (14.2)	88 (17.7)	-	-

[a] American Indian or Alaska Native, Asian, Native Hawaiian Pacific Islander, Middle Eastern, Other

[b] Gender queer, Transgender, Non-binary, Other