

# Washington PrEP DAP Client Survey

## Key findings, 2017

Washington State Department of Health  
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## Table of Contents

Acknowledgements.....	1
Overview.....	2
Summary of Findings.....	3
Demographic Characteristics.....	5
HIV Risk Behaviors.....	7
PrEP Use and Discontinuation.....	10
Sexual Behavior Change.....	13
Sexually Transmitted Infections Testing.....	15
PrEP Costs, Assistance and Coverage.....	17
Program Satisfaction.....	19
Limitations.....	20
Conclusions and Next Steps.....	21
References.....	22
Appendix A: PrEP Implementation Guidelines.....	23

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## Overview

Pre-exposure prophylaxis (PrEP) is an HIV prevention strategy that involves prescribing HIV medication to people who are HIV negative. Among those at high risk for HIV infection, PrEP can reduce the risk of infection by more than 90% [1, 3]. The Washington State PrEP Drug Assistance Program (PrEP DAP) was implemented by the Washington State Department of Health (DOH) in April 2014. PrEP DAP helps cover the cost of an HIV medication called Truvada. In order to qualify for the program, participants must have health insurance, reside in Washington, and fill out an application. The application form includes HIV risk factors, date of last HIV test to prove HIV negative status, and a portion that their healthcare provider completes.

In February 2017, DOH staff mailed a survey to all PrEP DAP participants with a valid mailing address, including those who were no longer enrolled. This was an effort to collect a variety of information about participants and their experiences with PrEP, including:

- Demographic characteristics
- HIV risk behaviors
- Costs associated with taking PrEP
- Barriers to accessing and taking PrEP
- Behaviors related to PrEP use, including adherence to Truvada, and changes in sexual behavior and HIV testing frequency.

The data from this survey will be used to strengthen PrEP DAP and to assess if other interventions and resources are needed for PrEP users in Washington State. Of the 1,006 surveys that were distributed, 264 were completed for a response rate of 26%. Clients that mailed back a completed survey were entered in a lottery to win 1 of 20 \$50 visa gift cards. The survey included a client identification number in order to enter participants into the lottery and to match with client-level enrollment data.

Thank you to all respondents for taking the time to complete the survey. This information will be used to improve PrEP DAP and inform other HIV prevention programs and services in Washington.

## Summary of Findings

### Demographic Characteristics

- 96% identified as male
- 91% identified as homosexual or gay
- 72% were non-Hispanic white, 12% were Hispanic/Latino, and 3% were non-Hispanic black
- 75% reported residence in King County, 18% in other Western Washington counties, 5% in Eastern Washington, and 3% in other states<sup>1</sup>
- The median age was 42
- 74% had a Bachelor's degree or higher
- The respondents who completed a survey (264) were demographically similar to the entire population to which the survey was sent (1,006)

### HIV Risk Behavior

- 95% were men who have sex with men (MSM)
- 25% of all respondents were in an ongoing sexual relationship with an HIV positive partner
- Among MSM in the past 12 months:
  - 41% used either methamphetamine or poppers
  - 79% had condom-less anal intercourse
  - 18% reported rectal gonorrhea or syphilis
  - 24% reported urethral gonorrhea or chlamydia

### PrEP Use and Discontinuation

- 85% were currently using PrEP, 14% had used it in the past and 1% never initiated it after enrolling in the program
- Median length of use was 19 months among current users; 12 months among past users
- Among those who discontinued PrEP, the most common reason for stopping was lower risk of HIV (78%), usually as the result of starting a new relationship (59%)
- Adherence to PrEP appeared to be high, with 92% reporting they took it on the day they completed the survey

### Sexual Behavior Change

- We observed an increase in risky sexual behaviors following the initiation of PrEP, including more sex partners per month (23%), less condom use (54%), and more receptive anal sex (23%)

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<sup>1</sup> Western Washington outside of King County includes the following counties: Clallum, Clark, Cowlitz, Grays Harbor, Island, Jefferson, Kitsap, Lewis, Mason, Pacific, Pierce, San Juan, Skagit, Skamania, Snohomish, Thurston, and Whatcom. Eastern Washington includes Adams, Asotin, Benton, Chelan, Douglas, Ferry, Franklin, Grant, Kittitas, Kootenai, Okanogan, Pend Orielle, Spokane, Stevens, Walla Walla, Whitman and Yakima counties.

Sexually Transmitted Infections (STI) Testing

- 56% reported getting tested for STIs every 3-6 months before starting PrEP, compared to 98% after starting PrEP
- 2% reported never getting tested before starting PrEP, compared to 0% after starting PrEP

PrEP Costs, Assistance and Healthcare Coverage

- 98% had health insurance
- 76% were enrolled in a patient assistance program (PAP)
- 56% didn't have monthly out-of-pocket (OOP) PrEP-related expenses. Among those who did, the mean was \$74 dollars.

## Demographic Characteristics

Demographic information was collected primarily through the survey, with only race, ethnicity, and age abstracted from enrollment data. Nearly all respondents identified as male (96%) and 91% identified as gay or homosexual. The majority of respondents resided in King County (75%), with the remaining reporting residence in Western Washington outside of King County (18%), Eastern Washington (5%) and out-of-state (3%). Seventy-two percent were non-Hispanic white, 12% were Hispanic and 3% were non-Hispanic black. The median age of survey participants was 42, with a range of 19 to 80. Respondents had a high level of educational attainment, with nearly three-quarters reporting a four-year college degree or higher. Sixty-three percent reported an annual household income of \$50,000 or higher and only 7% reported an income of less than \$20,000, with a median household size of 1. Table 1 displays the characteristics of respondents.

Respondents were compared to non-respondents on region of residence, race/ethnicity, gender identity, age, and enrollment status. The distributions were similar for region of residence, race/ethnicity and gender identity. A limitation of the comparison on region of residence and gender identity is this information can change over time, thus non-respondents zip code and gender identity may not be current. Survey respondents were older than non-respondents, with a median age of 42 compared to 37 ( $P<.0001$ ). The survey was mailed to all active and past program participants (total=1,006). Of the total distributed, 59% went to active and 41% to past participants. The majority of the 264 respondents were actively enrolled (71%), and the response rate was higher among those that were currently enrolled (32%), compared to those no longer enrolled (18%) ( $P<.0001$ ).

Washington PrEP DAP Client Survey, 2017

Table 1: Demographic Characteristics		
	%	n <sup>a</sup>
Region		
King County	74.8%	190
Other Western	17.7%	45
Eastern	4.7%	12
Out-of-state	2.8%	7
Gender Identity		
Male	95.8%	252
Female	1.9%	5
Non-binary/genderqueer	1.1%	3
Trans man	0.4%	1
Trans woman	0.8%	2
Sex at Birth		
Male	97.0%	256
Female	3.0%	8
Sexual Orientation		
Gay	91.3%	241
Bisexual	4.2%	11
Straight	2.3%	6
Queer	1.9%	5
Other	0.4%	1
Race/Ethnicity <sup>b</sup>		
White	72.0%	190
Hispanic	12.1%	32
Black	3.0%	8
Asian	8.7%	23
Multiple	2.7%	7
Unknown/Blank	1.5%	4
Foreign Born		
Yes	12.5%	32
No	87.6%	225
Education		
High school diploma/GED or less	5.0%	13
2-year degree/some college	21.7%	56
Bachelor's degree	37.6%	97
Higher degree	35.7%	92
Age		
19-29	14.0%	37
30-39	31.4%	83
40-49	24.6%	65
50-59	20.5%	54
60-80	9.5%	25
Annual Household Income		
<20,000	7.0%	18
20,000-39,999	17.9%	46
40,000-49,999	12.5%	32
50,000-74,999	23.7%	61
75,000-99,999	12.8%	33
≥100000	26.1%	67
Household Size	Median: 1	
<sup>a</sup> The number of respondents for each variable vary due to missing responses.		
<sup>b</sup> Hispanic respondents can be of any race, and all other racial groups are non-Hispanic.		

[Return to Table of Contents](#)



## HIV Risk Behaviors

In order to assess participants' reasons for taking PrEP, we asked a series of questions on risk behaviors associated with HIV. The questions were designed to align with Washington State PrEP Implementation Guidelines as best as possible (see Box 1 and Appendix A) [5]. These guidelines were developed to identify persons at highest risk of becoming infected with HIV [4]. The guidelines outline criteria for medical providers to initiate PrEP and criteria to discuss initiating PrEP with patients. There were some limitations based on the number of questions that could be included on the survey. Thus, certain risk measures were not completely captured. In particular, only one question was used to measure condom-less anal intercourse (CAI) outside of a mutually monogamous relationship and participants were not asked if their HIV positive partners are virologically suppressed or within 6 months of starting antiretroviral therapy (ART).

Ninety-five percent of males reported a history of sex with a man, and were categorized as men who have sex with men (MSM), of which 18% reported being diagnosed with rectal gonorrhea or syphilis, 24% reported urethral gonorrhea or chlamydia, 41% responded yes to using methamphetamine or poppers, 79% had CAI, and 2% provided sex in exchange for money or drugs, all within the past 12 months. A quarter of all respondents had an HIV positive sex partner, and of those 5% had a partner not on antiretroviral therapy (ART). Only 2% reported use of injection drugs in the past 12 months. The implementation guidelines were used to identify respondents at highest risk for HIV. Nearly half of respondents met the criteria for recommended use of PrEP, 39% met the criteria for discussing PrEP with a provider and 13% did not meet either set of criteria. Current PrEP users were more likely to meet the criteria for recommended use (51%) than those who had either never used PrEP or had used it the past (30%). Consistent with this pattern, only 9% of current users did not meet either of the guidelines, compared to 30% of non-users. The proportion of respondents who met the guidelines to discuss PrEP with a provider were similar among current users (39%) and non-users (40%). Table 2 shows HIV risk behaviors stratified by the PrEP implementation criteria.

Survey data were matched to the state's Sexually Transmitted Infections (STI) Surveillance Registry to compare STI diagnoses based on survey responses with those based on surveillance reports in the past 12 months. Twenty-nine percent of respondents were diagnosed with an STI (gonorrhea, chlamydia or syphilis) between February 15, 2016 and February, 15 2017. Sixteen percent were diagnosed with chlamydia, 17% with gonorrhea and 5% with syphilis. The majority of respondents who had a lab diagnosis in the year prior to completing the survey reported they had not been diagnosed with an STI (see Table 3). Fifty-five percent reported they had not been diagnosed with rectal gonorrhea in the previous 12 months and 46% reported they had not been diagnosed with urethral gonorrhea in the previous 12 months. The proportion with a lab diagnosis who did not report a diagnosis was also high for chlamydia and syphilis (40% and 67%, respectively).

Although similar HIV risk information is collected at time of enrollment, the data were not comparable to risk information collected on the survey. Risk factors can change over time, and

since the risk information is collected on the initial application and for annual renewals, it likely captures a different point in time than the survey. Furthermore, risk information collected on the application has changed over time, so program participants may have different data collected depending on their time of enrollment or renewal. Lastly, participants may be more likely or less likely to disclose risks behaviors when asked in the form of a question on the survey, rather than a “check all that apply” format on the application.

### Box 1. Washington State PrEP Implementation Guidelines

#### PrEP is recommended for individuals who meet the following criteria:

- Men and transgender persons who have sex with men and have any of the following risks:
  - o Diagnosis of rectal gonorrhea or early syphilis in the past 12 months
  - o Methamphetamine or popper use in the past 12 months
  - o History of providing sex in exchange for money or drugs in the past 12 months
- All persons in ongoing sexual partnerships with HIV positive partner(s) who are not taking or are within 6 months of starting ART, or who are not virologically suppressed<sup>a</sup>

#### Providers should discuss use of PrEP with individuals who meet the following criteria:

- Men and transgender persons who have sex with men and have any of the following risks:
  - o Have had CAI outside of a mutually monogamous long-term relationship with a man who is HIV negative<sup>b</sup>
  - o Diagnosis of urethral gonorrhea or rectal chlamydia in the past 12 months
- All persons who...
  - o are in ongoing sexual partnerships with HIV positive partner(s) who have been on ART for more than 6 months and are virologically suppressed<sup>a</sup>
  - o use injection drugs not prescribed by a medical provider
  - o are females with a history of providing sex in exchange for money or drugs
  - o are seeking a prescription for PrEP
  - o are completing a course of post-exposure prophylaxis (PEP) for non-occupational exposure to HIV
  - o are in HIV-serodiscordant relationships in which the female partner is trying to get pregnant

Not measured<sup>c</sup>

<sup>a</sup>The survey did not capture whether HIV positive partners were within 6 months of starting ART or whether they were virologically suppressed. The question only collected information on whether HIV positive partners were on ART.

<sup>b</sup>Respondents were asked whether they have had anal sex without a condom outside of a mutually monogamous relationship in the past twelve months. Definitions for mutually monogamous can vary, therefore this may not be the most accurate measure for CAI.

<sup>c</sup>These indications for PrEP were not measured in the survey

Washington PrEP DAP Client Survey, 2017

	Overall (N=264) <sup>a</sup> %	Current PrEP Use (N=224) <sup>a</sup> %	Past or Never PrEP Use (N=40) <sup>a</sup> %	P-Value
MSM <sup>b</sup>	95.1	85.7	14.3	0.1162 <sup>f</sup>
Rectal gonorrhea or syphilis (past 12 months) <sup>c</sup>	17.9	93.3	6.7	0.2777 <sup>f</sup>
Urethral gonorrhea or chlamydia (past 12 months) <sup>c</sup>	24.3	88.5	11.5	0.7072 <sup>f</sup>
Meth or poppers (past 12 months) <sup>c</sup>	41.0	88.3	11.7	0.3100 <sup>e</sup>
Exchanged sex (past 12 months) <sup>c</sup>	2.5	100.0	0.0	1.000 <sup>f</sup>
CAI <sup>c,d</sup>	79.1	89.6	10.4	0.0006 <sup>e</sup>
HIV positive partner(s)	38.9	96.0	4.0	0.0275 <sup>f</sup>
HIV negative partner(s)	79.9	89.0	11.0	0.7697 <sup>f</sup>
Partner(s) with unknown status	32.6	92.1	7.9	0.4414 <sup>e</sup>
HIV positive male partner(s) <sup>d</sup>	24.8	90.6	9.4	0.2399 <sup>f</sup>
Partner(s) on ART	96.9	90.5	9.5	1.0000 <sup>f</sup>
Partner(s) not on ART	4.6	100.0	0.0	1.0000 <sup>f</sup>
Unknown if partner(s) on ART	3.1	100.0	0.0	1.0000 <sup>f</sup>
Injection drug use (past 12 months)	1.94	80.0	20.0	0.5624 <sup>f</sup>
Females that exchanged sex (past 12 months)	--	--	--	--
PrEP Indication				0.0007 <sup>e</sup>
Recommend	48.1	90.5	9.5	
Discuss	39.3	84.5	15.5	
None	12.6	63.6	36.4	

<sup>a</sup>The number of respondents for each variable may vary due to missing responses.  
<sup>b</sup>MSM includes males who reported a history of sex with a man  
<sup>c</sup>Excluded to MSM  
<sup>d</sup>Categories are not mutually exclusive; respondents could select all options that applied.  
<sup>e</sup>Pearson  $\chi^2$  p-value  
<sup>f</sup>Fisher Exact  $\chi^2$  p-value

	Gonorrhea Lab Diagnosis (N=44) <sup>b</sup> %	Chlamydia Lab Diagnosis (N=40) <sup>b</sup> %	Syphilis Lab Diagnosis (N=13) <sup>b</sup> %
Self-Reported Rectal Gonorrhea or Syphilis Diagnosis			
Yes	43.2	--	61.5
No	54.6	--	30.8
I don't know	2.3	--	7.7
Self-Reported Urethral Gonorrhea or Chlamydia Diagnosis			
Yes	50%	58.1	--
No	45.5%	39.5	--
I don't know	4.6%	2.3	--

<sup>a</sup>Excluded to respondents who reported current PrEP use.  
<sup>b</sup>The number of respondents for each variable may vary due to missing responses.

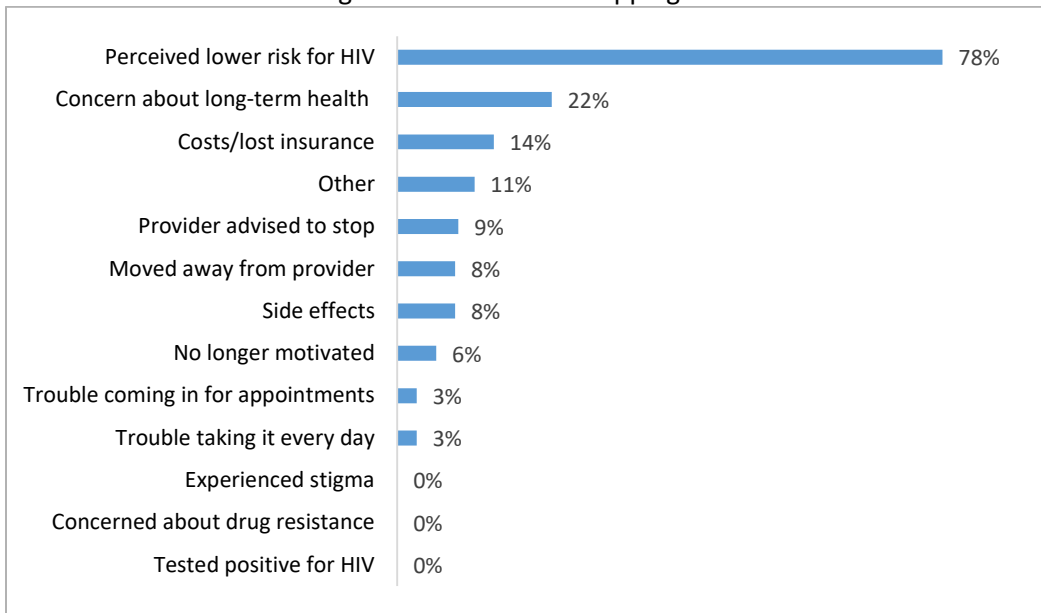
## PrEP Use and Discontinuation

Eighty-five percent of participants reported currently taking PrEP, while 14% had used it in the past and 1% never started it after enrolling in PrEP DAP. All respondents who reported PrEP use provided the date they started PrEP and the date they last took it (N=261). The median length of PrEP use among current PrEP users was 19 months, whereas the median length for those that discontinued PrEP was 12 months. The most commonly cited reason for stopping PrEP was perceived lower risk of HIV (78%), followed by concerns about long term health effects of PrEP (22%). Of those that indicated they stopped due to perceived lower risk of HIV, the primary reasons listed were starting a new relationship (59%) and having sex with fewer partners (38%). Figures 1 and 2 present the reasons for stopping PrEP and the reasons for perceived lower risk for HIV, respectively. Of the 1% that never initiated PrEP, the most prevalent reason was cost of taking PrEP (67%).

We asked current PrEP users a series of questions related to PrEP adherence. Ninety-two percent reported taking PrEP on the day they completed the survey. Sixty-five percent reported not having missed any doses of PrEP in the last 30 days, while 16% reported just one missed dose. The mean number of days current PrEP users missed taking Truvada in the last 30 days was 1, with a range of 0 to 24. The most common reason for last missed dose was forgetting to take it (41%). Thirty-one percent of current PrEP users reported they have never missed a dose of PrEP, in response to the question “The last time you missed taking PrEP, what were the reasons”? Figure 3 displays the reasons respondents attributed to missing the last dose of PrEP.

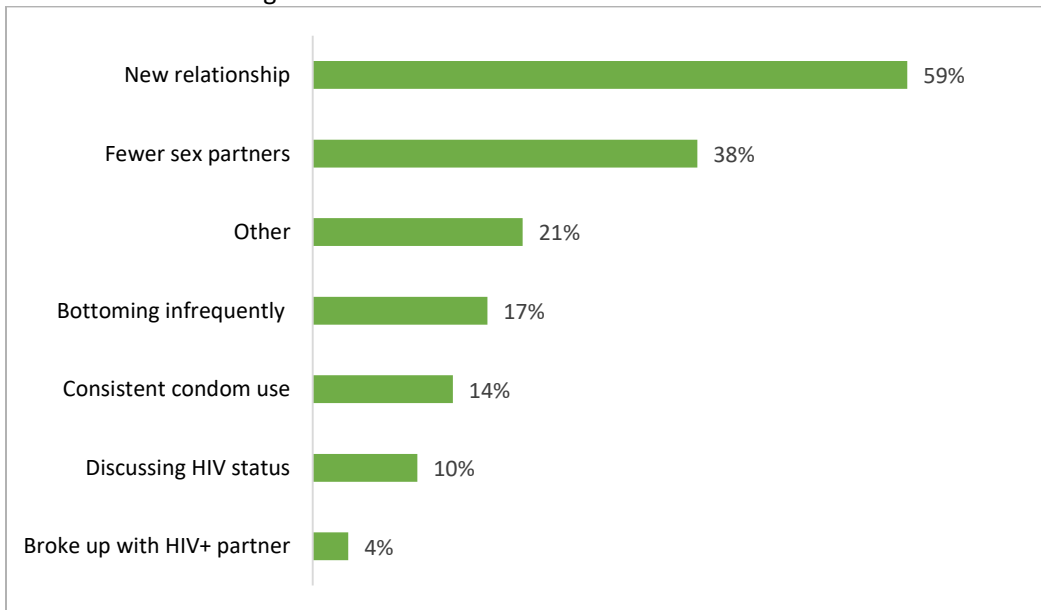
We asked clients how many minutes it usually takes to get to their PrEP providers office. The mean was 21 minutes for current PrEP users, with a median of 15 and a range of 2 to 90 minutes. For respondents who reported past use of PrEP, the mean and median were slightly higher, 26 and 20 respectively, with a range of 10 to 90 minutes. The mean length of time to reach their provider varied slightly by region of residence, though the difference was not significant. The mean was highest in Western Washington (29), followed by King County (21) and was lowest in Eastern Washington (15).

Figure 1: Reasons for Stopping PrEP



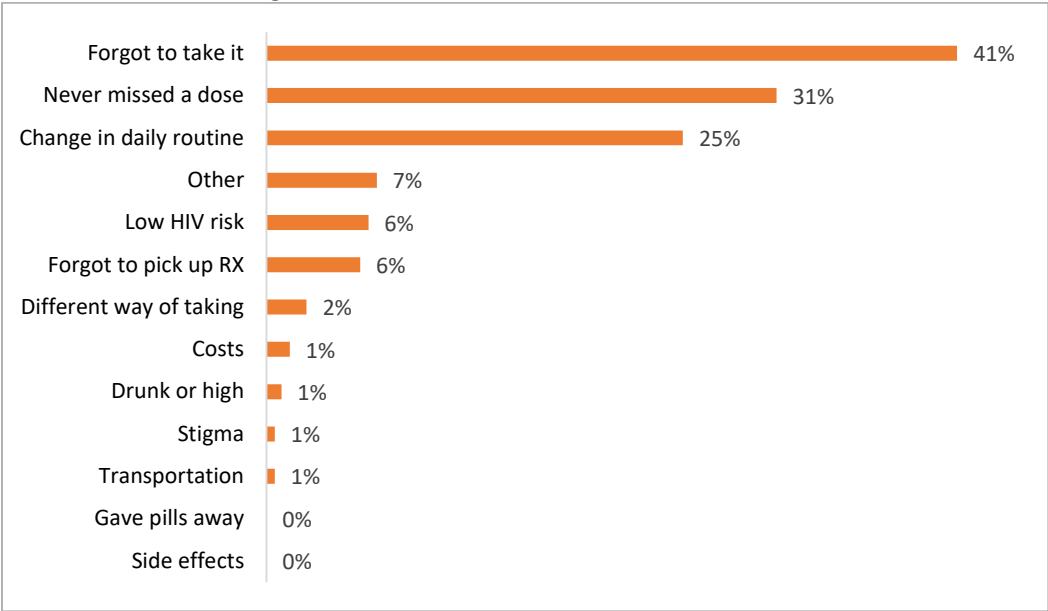
Notes. Excluded to respondents who reported past PrEP use. Categories are not mutually exclusive; respondents could select more than one option.

Figure 2: Reasons for Perceived Lower Risk for HIV



Notes. Excluded to respondents who selected perceived lower risk for HIV as a reason for stopping PrEP. Categories are not mutually exclusive; respondents could select more than one option.

Figure 3: Reasons for Last Missed Dose of PrEP



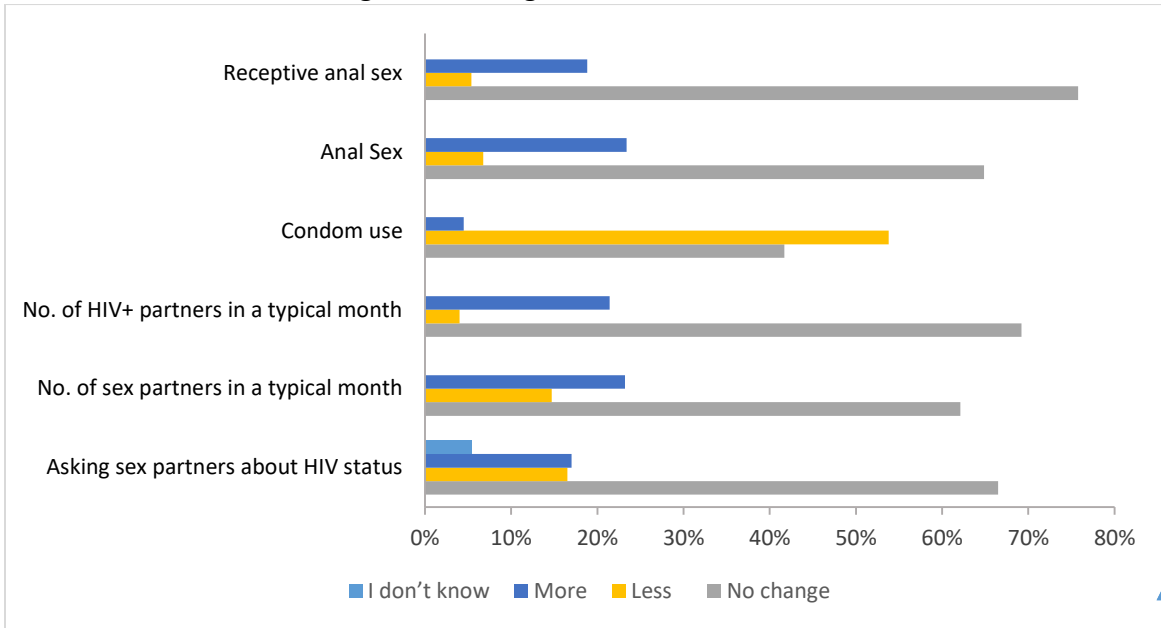
Notes. Excluded to respondents who reported current PrEP use. Categories are not mutually exclusive; respondents could select more than one option.

## Sexual Behavior Change

We asked respondents who reported current use of PrEP questions about changes in HIV risk behaviors before versus after starting PrEP. We observed an association between taking PrEP and sexual behavior for each of the sexual behavior change questions. While the majority of current PrEP users reported no change in behavior for all but one of the behavior change questions, those who reported a change were more likely to report an increase in high risk behavior after starting PrEP than a decrease (see Table 4). We observed an increase in the total number of sex partners and the number of HIV positive sex partners in a typical month, a decrease in condom use, and an increase in frequency of anal sex and receptive anal sex. Figure 4 presents the proportion that reported no change, an increase or a decrease for each of the behavior change question.

Table 4: Sexual Behavior Before Versus After Starting PrEP <sup>a</sup>			
	%	n <sup>b</sup>	p-value <sup>c</sup>
Asking sex partners about their HIV status			<.0001
No change	66.5	145	
Less often	16.5	36	
More often	17.0	37	
Number of sex partners in a typical month			<.0001
No change	62.1	139	
Fewer partners	14.7	33	
More partners	23.2	52	
Number of HIV positive sex partners in a typical month			<.0001
No change	69.2	155	
Fewer partners	4.0	9	
More partners	21.4	48	
Status of partners unknown	5.4	12	
Condom use for anal sex			<.0001
No change	41.7	93	
Less often	53.8	120	
More often	4.5	10	
Anal sex			<.0001
No change	64.9	144	
Less often	6.8	15	
More often	23.4	63	
Receptive anal sex			<.0001
No change	75.8	169	
Less often	5.4	12	
More often	18.8	42	
<sup>a</sup> Excluded to respondents who reported current PrEP use.			
<sup>b</sup> The number of respondents for each variable vary due to missing responses.			
<sup>c</sup> Pearson $\chi^2$ p-value			

Figure 4: Change in HIV Risk Behaviors



Note. Restricted to respondents who reported current PrEP use.



## Sexually Transmitted Infections Testing

Survey participants who reported current PrEP use were asked, in an average year, how often they got tested for STIs before starting PrEP, and how often they get tested while on PrEP. Prior to starting PrEP, 56% reported testing at the recommended 3-6 months interval (see Box 2), 30% reported getting tested once a year, 11% less than once a year and 2% never. Testing frequency increased after respondents started PrEP, with 98% testing every 3-6 months. Figure 5 displays STI testing frequencies before versus after PrEP. There was a significant difference between getting tested every 3-6 months versus less often (once a year, less than once a year, or never) before starting PrEP compared to while taking PrEP ( $p < .0001$ ).<sup>2</sup>

Survey data were matched to STI surveillance data to look at testing frequency and reason for testing among respondents who had an STI diagnosis in the previous year. Frequent STI testing before starting PrEP was higher among respondents who had either a lab or self-reported STI diagnosis. Sixty-five percent of respondents with a lab diagnosis of any STI in the past 12 months got tested every 3-6 months, compared to 52% without a diagnosis. Similarly, 65% of respondents who reported an STI diagnosis in the past 12 months got tested every 3-6 months, compared to 51% without a self-reported diagnosis. The most common reason for testing among those with a lab diagnosis was due to symptoms of an STI (47%), followed by a routine check-up (31%) and having a partner with an STI (11%).

In an analysis evaluating whether PrEP DAP clients were diagnosed with more STIs in the year after enrolling in PrEP DAP compared to the year before, PrEP DAP clients were matched to STI surveillance data to observe the number of diagnoses before versus after enrollment. The odds of being diagnosed with an STI while enrolled in PrEP DAP for one year were 4.6 times higher than being diagnosed in the year prior to enrollment. The results of the survey suggest that the higher rate of diagnoses among PrEP users may in part be due to more frequent testing for STIs.

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<sup>2</sup> McNemar's exact test; compares whether taking PrEP has an effect on STI testing frequency.

### Box 2. STI Testing Information

Centers for Disease Control (CDC) guidelines recommend that sexually active men who have sex with men test for syphilis, chlamydia, gonorrhea and HIV at least once a year [2]. All patients receiving PrEP should be tested for HIV at least every 3 months [6]. MSM who have multiple or anonymous partners should be screened every 3-6 months for STIs and all sexually active MSM may benefit from STI testing at 3-6 month intervals [2].

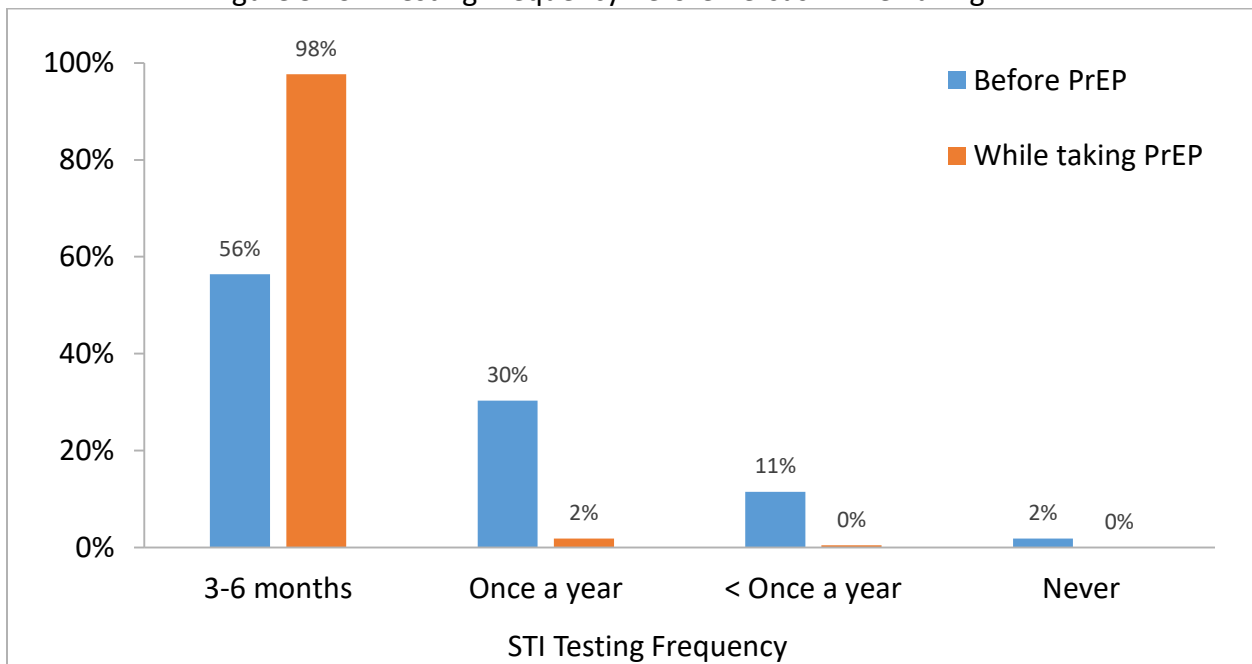
To learn more about HIV and STI testing, and to find out where you can get tested, follow these links:

<http://www.doh.wa.gov/YouandYourFamily/IllnessandDisease/HIVAIDS/Prevention/Testing>

<http://www.doh.wa.gov/YouandYourFamily/IllnessandDisease/SexuallyTransmittedDisease/GettingTested>

<http://www.kingcounty.gov/depts/health/communicable-diseases/hiv-std/patients/testing.aspx>

Figure 5: STI Testing Frequency Before Versus While Taking PrEP



Note. Restricted to respondents who reported current PrEP use.

## **PrEP Costs, Assistance and Coverage**

Respondents who reported current use of PrEP completed a portion of the survey on healthcare coverage and costs associated with PrEP use. The population of current PrEP users was highly insured, with 98% reporting they had health insurance. Health insurance is a requirement for enrolling in PrEP DAP, however in special circumstances PrEP DAP will cover uninsured clients. Only 1% of current PrEP users reported they did not have insurance. It is possible that current PrEP users are more likely to have health insurance, as it is a requirement for PrEP DAP and based on a comparison to non-respondents, in which 10% claimed they did not have health insurance. Seventy-five percent were enrolled in a patient assistance program (PAP) in addition to PrEP DAP, with the majority receiving assistance from the Gilead Co-pay Advancing Access Program (88%). Respondents were asked to estimate their average monthly out-of-pocket (OOP) costs to take PrEP. Fifty-six percent reported they did not pay anything for PrEP. Of those that had monthly expenses, the mean was \$74 and the median was \$45, with a range of \$7 to \$1,000. Respondents were also asked to select all OOP PrEP-related costs, which included full prescription, medical and lab costs, and co-pays for prescription, medical and lab services. The majority of respondents did not report full-pay expenses, however there appeared to be some uncertainty around this question as several respondents selected both co-pays and full expenses, which is inconsistent with health insurance plans. Nearly 50% claimed to have medical and lab co-pays, and almost a quarter reported pharmacy co-pays, however PrEP DAP covers clients' pharmacy co-pays. The data from PrEP costs related questions suggest respondents may have some uncertainty about what is covered under their insurance plan, PrEP DAP, and PAPs, therefore results should be interpreted with caution.

Washington PrEP DAP Client Survey, 2017

Table 5: PrEP Costs, Assistance and Coverage <sup>a</sup>		
	%	n <sup>b</sup>
<b>Insured</b>		
Yes	97.8	218
No	1.4	3
Unknown	0.9	2
<b>Enrolled in PAP</b>		
Yes	75.5	166
No	18.6	41
Unknown	5.9	13
<b>PAP type</b>		
Gilead Co-Pay Coupon Program	88.0	146
Gilead Patient Assistance Program	3.0	5
Patient Advocate Foundation Co-Pay Relief Program	1.2	2
Patient Access Network	7.2	12
<b>Out-of-pocket costs</b>		
Full prescription costs	2.2	5
Prescription co-pays	23.2	52
Full medical visit costs	5.8	13
Medical visit co-pays	46.4	104
Full lab costs	10.3	23
Lab costs co-pays	48.7	109
Other	3.6	8
Unknown	1.3	3
None	35.3	79
<b>Monthly OOP</b>		
0	55.6	119
7-20	10.3	22
25-50	18.7	40
53-75	4.2	9
80-100	7.1	13
110-1,000	5.1	11
<sup>a</sup> Excluded to respondents who reported current PrEP use.		
<sup>b</sup> The number of respondents for each variable vary due to missing responses.		

## Program Satisfaction

Eighty percent of respondents reported being either satisfied or very satisfied with PrEP DAP. Thirteen percent reported being very dissatisfied, however it is possible that some of these respondents meant to select very satisfied, based on the observation that several respondents selected very dissatisfied and then wrote positive comments about the program in the optional comment box. Additionally, several respondents first selected very dissatisfied then crossed it out and selected very satisfied. The order in which response options were presented may have influenced respondents' selection (order is the same as shown in Table 6). While there was no difference between individuals who reported current PrEP use and individuals who reported past or never use in feeling very dissatisfied with the program, current users were more likely to report feeling very satisfied (64%) and less likely to report being neither satisfied or dissatisfied (5%), compared to those who had never used or discontinued PrEP (43% and 20%, respectively).

An optional comment box was provided for respondents to give feedback on ways to improve PrEP DAP. While the majority of respondents wrote positive feedback in the comment box, there were several suggestion on ways to improve the program. The most common theme was related to cost of taking PrEP. Several respondents stated they would like all lab costs covered for STI and HIV tests, or the option to test outside of a visit with their provider. Furthermore, several respondents wrote comments related to communication and marketing, including increased marketing to specific populations at high risk for HIV and to physicians across the state, better communication about the enrollment process and working with providers and pharmacies to provide a more seamless experience. Additionally, there were several comments about offering the application, other forms and surveys electronically. There was a lot of valuable feedback provided in the comments box that will be reviewed by PrEP DAP staff to strengthen the program.

	Overall (N=261) %	Current PrEP Use (N=221) %	Past or Never PrEP Use (N=40) %	P-Value
Program Satisfaction				0.0034
Very dissatisfied	12.6	12.7	12.5	
Dissatisfied	0.8	0.5	2.5	
Neither satisfied or dissatisfied	6.9	4.5	20.0	
Satisfied	18.8	18.1	22.5	
Very satisfied	60.9	64.3	42.5	

## **Limitations**

The survey may not be generalizable to all PrEP DAP clients due to the moderately low response rate. The individuals who responded to this survey may have different characteristics than non-respondents. The survey was mailed out, rather than offered online, because very few email addresses were on file. PrEP DAP clients may have been less likely to complete a mail-in survey than an electronic survey, which could have affected sample size. Furthermore, clients currently enrolled in the program had a higher response rate than individuals no longer enrolled, and it is likely enrollment status affected survey completion. Clients who were regularly receiving correspondence from PrEP DAP staff may be have been more likely to open the survey and complete it. Furthermore, Individuals who reported current PrEP use were more likely to respond than individuals who reported they were no longer taking PrEP, which may indicate that respondents were at higher risk for HIV than those who did not complete the survey.

## Conclusions and Next Steps

This survey has provided valuable information which helps us better understand PrEP adherence, barriers to taking PrEP, and changes in sexual behavior and STI testing among those who reported current PrEP use. The survey was distributed to all current and past PrEP DAP clients, and the response rate was 26%. Overall, HIV risk indicators were in alignment with the Washington State PrEP Implementation Guidelines. Nearly half of respondents met the guidelines for recommended use of PrEP and 39% met the recommendation to discuss PrEP with a provider. Adherence to Truvada appeared to be high, based on data from questions used to measure adherence. Routine testing for STIs was common and increased after starting PrEP, with nearly all respondents reporting getting tested every 3-6 months. PrEP DAP participants did not appear to be paying a lot of money out of pocket. Over half of survey participants reported they did not pay anything to take PrEP, while those that reported an estimated monthly OOP had a mean of \$74. PrEP DAP participants are satisfied with the program. While the majority of respondents reported being very satisfied with the program, results should be interpreted with caution due to potential bias introduced by the order in which response options were displayed.

The results of the survey will be reviewed by program staff to improve the program by addressing barriers to taking Truvada, such as cost, improving communication by offering electronic applications and educating clients on patient assistance programs, and increasing outreach efforts to engage with providers and persons interested in taking PrEP about PrEP DAP and other sources of patient assistance for Truvada. We plan to conduct a similar survey on an annual basis to continue collecting data on behaviors and practices associated with taking PrEP. We hope to conduct the survey electronically in 2018, or to at least provide program participants the option to complete it online. We value the data and feedback that respondents provided on the survey, and appreciate the time and effort taken to complete the survey.

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## Appendix A

### Public Health – Seattle & King County & Washington State Department of Health PrEP Implementation Guidelines 2015

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These guidelines provide local guidance defining priority populations for HIV PrEP, and are designed to complement the U.S Public Health Service PrEP guidelines<sup>1</sup>. Close to 80% of all HIV infections in Washington State, including in King County, occur in men who have sex with men (MSM), and MSM are the primary candidate population for PrEP use in the area.

#### Identifying persons in whom to consider PrEP:

1. Public Health recommends that medical providers routinely ask all adolescent and adult patients if they have sex with men, women or both men and women.
2. Providers should ensure that all of their patients who are MSM or transgender persons who have sex with men know about PrEP.

Analyses of local data suggest that the strongest risk factors for HIV acquisition among MSM are methamphetamine or popper use and having rectal gonorrhea or early syphilis<sup>2</sup>, and these analyses have helped inform local guideline development. Local MSM with these risk factors have an incidence of HIV exceeding 3% per year. The estimated incidence of HIV among all MSM in King County is approximately 0.5%.

#### Guidelines for initiating PrEP in HIV-uninfected persons:

##### Medical providers should recommend that patients initiate PrEP if they meet the following criteria:

3. MSM or transgender persons who have sex with men if the patient has any of the following risks:
  - Diagnosis of rectal gonorrhea or early syphilis in the prior 12 months.
  - Methamphetamine or popper use in the prior 12 months.
  - History of providing sex for money or drugs in the prior 12 months.
4. Persons in ongoing sexual relationships with an HIV-infected person who is not on antiretroviral therapy (ART) **OR** is on ART but is not virologically suppressed **OR** who is within 6 months of initiating ART.

#### References

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##### Medical providers should discuss initiating PrEP with patients who have any of the following risks:

1. MSM and transgender persons who have sex with men if the patient has either of the following risks:
  - Condomless anal sex outside of a long-term, mutually monogamous relationship with a man who is HIV negative. Unprotected receptive anal sex is associated with a higher risk of HIV acquisition than unprotected insertive anal sex, and some authorities recommend PrEP to all men who have unprotected receptive anal intercourse outside of a mutually monogamous relationship with an HIV-uninfected partner<sup>3</sup>.
  - Diagnosis of urethral gonorrhea or rectal chlamydial infection in the prior 12 months.
2. Persons in HIV-serodiscordant relationships in which the female partner is trying to get pregnant.
3. Persons in ongoing sexual relationships with HIV infected persons who are on antiretroviral therapy and are virologically suppressed.
4. Women who provide sex for money or drugs.
5. Persons who inject drugs that are not prescribed by a medical provider.
6. Persons seeking a prescription for PrEP.
7. Persons completing a course of antiretrovirals for non-occupational exposure to HIV infection.

As with all medical therapies, patients and their medical providers ultimately need to decide what treatments and preventive measures are best for them. Providers should evaluate patients' knowledge and readiness to initiate PrEP prior to prescribing tenofovir and emtricitabine, and should counsel and educate patients to facilitate their success taking PrEP. Medical providers should refer to national guidelines (see below) for information on how to prescribe PrEP and monitor persons on PrEP<sup>1</sup>.