

# PrEP Patient Survey Report

March 2020

## I. Summary

PrEP stands for pre-exposure prophylaxis, a daily pill that can help prevent HIV. Since June 2016, the Virginia Department of Health (VDH) funded more than 30 local health departments and other organizations to support clinical PrEP services across Virginia. In 2019, the VDH Division of Disease Prevention (DDP), surveyed a sample of PrEP patients to understand what influenced patients' initiation of PrEP, medication adherence and participation in the program. Seventy-eight patients responded to the survey – 48 previous patients and 30 current patients.

Results showed that most patients learned about PrEP from a healthcare provider. Healthcare providers were also the most important influencer in patients' decisions to get on PrEP. Advertisements, friends and romantic partners were also important influences in helping patients learn about PrEP, decide to learn more about PrEP and decide to get on PrEP.

Twenty-five percent of current patients reported missing a pill in the last month, and 10% reported missing a pill in the past 7 days, meaning 90% reported recent daily PrEP adherence. While 10-25% struggled somewhat with adherence, 50-60% of PrEP patients have discontinued the program, indicating that program attrition seems more common than PrEP non-adherence.

The leading barrier to non-adherence was side effects, with 44% of patients reporting that side effects made it hard to take PrEP and 27% reporting they quit PrEP due to side effects. Forgetting was the second most common barrier to taking PrEP, reported by nearly 30% of patients. Nearly 20% of patients reported stigma as a barrier to adherence. One-third of patients reported having mental health challenges and approximately 10% reported intimate partner violence, homelessness and/or a substance use condition, which could impact adherence. In addition, one in four new PrEP patients had doubts that they were at risk for HIV and more than 50% felt only 'somewhat' or 'not ready' for PrEP. This lack of readiness could predispose PrEP patients to discontinuing the program especially if they face other barriers.

The survey pointed to the need to continue to support the role of healthcare providers in promoting PrEP and to continue to advertise PrEP. Opportunities exist to focus on the role of friends and romantic partners in supporting PrEP patients. Other opportunities for improvement include better addressing the side effects of PrEP, giving all patients adherence tools such as pill boxes and other reminder devices and apps, and regularly assessing barriers to medication adherence and helping patients devise a plan. Assessing patients' readiness for PrEP and supporting new patients early and often should be considered.

The full benefits of PrEP as an HIV prevention tool can only be realized if the program can recruit and retain patients most in need of the program, and support patients' medication adherence. The findings and recommendations can help inform short-term and longer-term planning activities to help maximize the impact of the program.

## II. Introduction

PrEP stands for pre-exposure prophylaxis, a daily pill that can help prevent HIV. Since June 2016, the Virginia Department of Health (VDH) has provided funding to more than 30 clinics at local health departments and other healthcare organizations to support clinical PrEP services across the Commonwealth of Virginia. In addition, PrEP was made available at no cost to patients through December of 2019. As of that time, 1,196 patients had been prescribed PrEP through the VDH PrEP Program. PrEP retention and adherence are critical to maximizing the effectiveness of PrEP as an HIV prevention strategy. Available data shows that approximately 50-60% of VDH PrEP patients have discontinued the VDH PrEP Program. Prior to this survey, VDH did not have data regarding PrEP patients' adherence to the medication regimen of taking one pill daily.

The goals of this survey were to understand what influences patients to initiate PrEP, with a special focus on what factors influence patients' medication adherence and participation in the PrEP program. The Division of Disease Prevention (DDP) was interested in understanding how patients initially heard about PrEP, what helped patients decide to learn more and try to get on PrEP, patient behaviors and barriers related to daily PrEP medication adherence, and patients' clinic experiences related to adherence. DDP will use the findings to identify strategies to improve program recruitment and retention as well as improve PrEP medication adherence.

## III. Methodology

DDP conducted a survey of previous and current PrEP patients who received services from DDP funded PrEP clinics across Virginia. A random sample of 300 patients (50% previous and 50% current patients) who have been served since January 2017 were invited to participate in a 35 question REDCap survey. The instrument was developed based on applicable health behavior theories and models (e.g. Health Belief Model), program goals, adherence tools and best practices identified via literature review.

Patients were invited to participate via a letter with a REDCap survey link enclosed and were offered the incentive of a \$25 gift card. Strategies were developed and put into place to validate surveys and reduce the possibility of fraudulent responses. Patients who did not respond to the first invitation received up to two additional invitations. The survey invitation was in English and Spanish; patients were given a phone number to call if they wanted to do the survey on the phone and/or in Spanish. PrEP clinic staff were made aware of this survey and asked to help promote awareness of the survey and encourage patients to complete the survey if they received an invitation. This survey received approval from the VDH Institutional Review Board. A copy of the full study protocol is available for further information about the methodology.

## IV. Results

Data were analyzed using descriptive statistics. Tables in the results section are presented in descending order from most responses to least responses. For tables with multiple response categories, an arrow indicates the category presented in descending order. Respondents'

written responses in ‘other’ categories or in response to open-ended questions are presented as written, uncorrected for grammar or spelling.

### SECTION 1: Response Rate

Out of 300 mailed survey invitations, 28.6% (N=86) were returned to sender due to incorrect addresses or the patient not living at that address any more. Out of the 214 surveys that were received at the patient’s addresses, 78 were completed for a response rate of 36.4%. Of the completed surveys, 38.5% (N=30) were from current PrEP patients and 61.5% (N=48) were from previous PrEP patients who were no longer participating in the program.

### SECTION 2: Demographics

Respondents were, on average, 33.9 years old and had an average income of \$ 35,564. Respondent demographics appear to mirror the PrEP population of patients as a whole. See Table 1 below.

<b>Table 1. Respondent Demographics</b>	
<b>Gender</b>	<b>% of Respondents</b>
Male	71.8%
Female	17.9%
Transgender, male to female	2.6%
Transgender, female to male	0.0%
Gender nonconforming	3.8%
Declined to answer	3.8%
TOTAL	100.0%
<b>Sexual orientation</b>	<b>% of Respondents</b>
Gay or homosexual	53.8%
Bisexual	25.6%
Straight or heterosexual	19.2%
No response	1.3%
TOTAL	100.0%
<b>Race</b>	<b>% of Respondents</b>
American Indian or Alaska Native	0.0%
Asian	3.8%
Black or African American	35.9%
Native Hawaiian or Pacific Islander	1.3%
White	44.9%
Other	3.8%
No response	10.3%
TOTAL	100.0%
<b>Ethnicity</b>	<b>% of Respondents</b>
Hispanic	2.6%
Non-Hispanic	97.4%

### SECTION 3: Learning and Deciding About PrEP

This section includes results about how PrEP patients initially heard about PrEP and what helped them decide to learn more and try to get on PrEP.

- A. **How patients first heard about PrEP:** When asked, “How did you **first** hear about PrEP?” the leading response was a healthcare provider (33.3%), followed in equal measure by a friend (20.5%) and an advertisement (20.5%).

<b>Table 2. How did you first hear about PrEP?</b>	<b>% of Patients (N=78)</b>
A healthcare provider (for example, a doctor or nurse)	33.3%
A friend	20.5%
An advertisement (for example, on social media, TV, radio, bus or billboard)	20.5%
A romantic or sexual partner	11.5%
DIS worker	6.4%
Other – See below*	5.1%
A family member	2.6%
<b>TOTAL</b>	<b>100.0%</b>

\*Other responses: “LGBT Center Norfolk, VA, Local gay community center, news article, walk in clinic”

- B. **Sources of PrEP Information:** When asked “Have you heard about PrEP from **any** of these sources? Check all that apply”, each respondent had heard about PrEP from, on average, 2.25 sources. A health care provider and advertisements were leading responses, at 59.0% each, followed by a friend (44.9%) and a romantic or sexual partner (34.6%).

<b>Table 3. Have you heard about PrEP from any of these sources? Check all that apply.</b>	<b>N Responses</b>	<b>% of Patients Selecting This Option</b>
A healthcare provider (for example, a doctor or nurse)	46	59.0%
An advertisement (for example, on social media, TV, radio, bus or billboard)	46	59.0%
A friend	35	44.9%
A romantic or sexual partner	27	34.6%
Disease Intervention Specialist (DIS) worker	14	17.9%
Other*	6	7.7%
A family member	3	3.8%
<b>TOTAL:</b>	<b>176</b>	<b>-</b>

\*Other: “General knowledge in the community, studies; LGBT Life Center; Magazine; News Article; Walk-in vdh”

- C. **Deciding to learn more about PrEP:** When asked, “Which information source(s) helped you decide to learn more about PrEP? Check all that apply,” a healthcare provider was again the leading response, chosen by nearly 63% of PrEP patients. The second most common

response was “A friend” at 30.8%, and the third sources, at 21.8% each, were “a romantic or sexual partner” and “an advertisement”.

<b>Table 4. Which information source(s) helped you decide to learn more about PrEP? Check all that apply.</b>	<b>N</b>	<b>% of Patients Selecting This Option</b>
A healthcare provider (for example, a doctor or nurse)	49	62.8%
A friend	24	30.8%
A romantic or sexual partner	17	21.8%
An advertisement (for example, on social media, TV, radio, bus or billboard)	17	21.8%
Disease Intervention Specialist (DIS) worker	13	16.7%
Other*	6	7.7%
A family member	5	6.4%
<b>TOTAL</b>	<b>131</b>	<b>-</b>

\*Other: “Aids; Internet; LGBT Life Center; Local gay community center; Trainings; Wanting - safe sex.”

**D. Factors influencing decision to get on PrEP:** When asked “What helped you decide to try to get on PrEP? Check all that apply,” the response selected by the most patients was “I wanted to feel more protected” (60.3%). Being encouraged by a healthcare provider (52.6%) and PrEP being available at no cost (46.2%) were other leading factors.

<b>Table 5. What helped you decide to try to get on PrEP? Check all that apply.</b>	<b>N</b>	<b>% of Patients Selecting This Option</b>
I wanted to feel more protected	47	60.3%
I was encouraged by a healthcare provider (for example, a doctor or nurse)	41	52.6%
It was free and I did not have to pay for it	36	46.2%
Someone I know had HIV	22	28.2%
My partner encouraged me to get on PrEP	17	21.8%
I got information from an advertisement (for example, on social media, TV, radio, bus or billboard)	13	16.7%
I was encouraged by my family or friends	12	15.4%
Other	0	0%
<b>TOTAL</b>	<b>188</b>	<b>-</b>

**E. Deciding to get on PrEP:** When asked “What was the single greatest reason you decided to try to get on PrEP?” the leading response was “I wanted to feel more protected (51.3%). Being encouraged by a healthcare provider (12.8%) and someone they knew having HIV (10.3%) were the 2<sup>nd</sup> and 3<sup>rd</sup> top reasons, respectively.

<b>Table 6. What was the <u>single greatest reason</u> you decided to try to get on PrEP?</b>	<b>% of Patients (N=78)</b>
I wanted to feel more protected	51.3%
I was encouraged by a healthcare provider	12.8%
Someone I know had HIV	11.5%
It was free and I did not have to pay for it	9.0%
My partner encouraged me to get on PrEP	7.7%
I was encouraged by my family or friends	3.8%
I got information from an advertisement	3.8%
<b>TOTAL</b>	<b>100.0%</b>

#### SECTION 4: PREP RETENTION AND ADHERENCE

This section will examine the results related to patient behaviors and barriers related to daily PrEP medication adherence and their clinic experiences related to adherence.

**F. PrEP adherence rate:** *Note: These questions were asked of current PrEP patients only.*

In their responses to questions about adherence, 23% of current PrEP patients (n=7) reported that they missed at least one PrEP pill in the past 30 days, and 10% of current PrEP patients (n=3) reported missing at least one PrEP pill in the past 7 days. When asked how confident they were that they could continue to take PrEP every day, 86.7% of current PrEP patients felt mostly or very confident but 13.3% were only somewhat confident. See Table 7 below.

<b>Table 7. How confident are you that you can continue to take PrEP every day?</b>	<b>% of Current PrEP Patients (N=30)</b>
Very confident	60.0%
Mostly confident	26.7%
Somewhat confident	13.3%
Not confident	0.0%
<b>TOTAL</b>	<b>100%</b>

**G. Barriers to adherence:** When asked, “Did any of the following ever make it hard for you to take PrEP?” over 43% of patients said side effects made it hard to take PrEP, at least at some point. That was the leading response, followed by forgetting to take PrEP (29.5%), the patient feeling they were not at risk for HIV (25.6%) and stigma (19.2%). Between 10%-14% of patients selected at least one clinical/ logistical barrier to adherence, noted with an asterisk. See Table 8 below.

<b>Table 8. Did any of the following ever make it hard for you to take PrEP?</b>	<b>Yes categories combined</b>	Yes - definitely	Yes - somewhat	No not really	TOTAL
I did not like the side effects	43.6%	25.6%	17.9%	56.4%	100.0%
I forgot to take my pill	29.5%	6.4%	23.1%	70.5%	100.0%
I felt I was not at risk for HIV	25.6%	10.3%	15.4%	74.4%	100.0%
I did not want people to know I was taking it (stigma)	19.2%	7.7%	11.5%	80.8%	100.0%
*The clinic was closed when I could go there	14.1%	3.8%	10.3%	85.9%	100.0%
*I did not have transportation to the clinic	11.5%	5.1%	6.4%	88.5%	100.0%
*I would run out of pills before I had a new bottle	10.3%	7.7%	2.6%	89.7%	100.0%
It was a hassle / inconvenient	9.0%	1.3%	7.7%	91.0%	100.0%
I was already taking too many other medicines	6.4%	5.1%	1.3%	93.6%	100.0%

The rate at which previous PrEP patients reported that feeling “not at risk for HIV” as a factor that made it hard to take PrEP was more than double the rate (33.3%) as that of current PrEP patients (13.3%). See Table 9.

<b>Table 9. Current and Previous PrEP Patients’ Feeling “Not at risk for HIV” Made It Hard to Take PrEP</b>				
<b>Current PrEP patient?</b>	<b>Yes categories combined</b>	<b>Yes - definitely</b>	<b>Yes - somewhat</b>	<b>No not really</b>
Yes	13.3%	6.7%	6.7%	86.7%
No	33.3%	12.5%	20.8%	66.7%

H. **Cycling on and off:** More than one-third of PrEP patients (35.9%, n=28) reported they stopped taking PrEP for more than 14 days and then re-started. They were off PrEP for an average of 65 days (range: 14-365) before re-starting PrEP. The leading reason for stopping PrEP was forgetfulness (21.4%). See table below.

<b>Table 10. Reason for Stopping PrEP before Re-Starting</b>	<b>% of Patients (N=28)</b>
I kept forgetting to take my pills	21.4%
Other^ (see below)	21.4%
I felt like I was not at risk for HIV	7.1%
*The clinic was closed when I could go there	7.1%
I did not want people knowing I was taking it	3.6%
It was a hassle / inconvenient	3.6%
*I did not have transportation to the clinic	3.6%
I was already taking too many other medicines	3.6%
I did not like the side effects	2.9%
<b>TOTAL</b>	<b>100.0%</b>

\*Logistical barriers; ^Other: Aging issues; had surgery; lost insurance; no access to doctor or money; The clinic where I would get it [---] they would ALWAYS have an excuse/reason why it

was delayed; The person who was supposed to order my meds wasn't ordering them and then wasn't informing me that they were in

- a. **Reasons for re-starting PrEP:** Patients who stopped and re-started PrEP were also asked “What made you re-start taking PrEP?” The leading answer was wanting to feel more protected (42.9%). See table below.

<b>Table 11. What made you re-start taking PrEP?</b>	<b>% of Patients (N=28)</b>
I wanted to feel more protected	42.9%
It was free and I did not have to pay for it	14.3%
Other^	10.7%
Someone I know had HIV	7.1%
I was encouraged by my family or friends	3.6%
My partner encouraged me to get on PrEP	3.6%
I got information from an advertisement	3.6%
I was encouraged by a healthcare provider	1.4%
<b>TOTAL</b>	<b>100.0%</b>

^Responses indecipherable

- I. **Full bottle non-adherence:** When asked “Have you ever filled a PrEP prescription but then you did not take any of the pills,” 14% of PrEP patients (n=11) said “Yes”? Selected reasons included not feeling at risk or HIV, not liking the side effects and forgetting to take the pills. Other write-in reasons included: *“the health department made me feel like a test subject, my privacy was invaded...; I remained celibate during the time I was on prep.”*
- J. **Reasons for quitting PrEP:** Out of the 78 respondents, 61.5% (n=48) had quit the VDH PrEP program. The main reason was not liking the side effects (27.1%) followed by feeling that they weren’t at risk for HIV (18.8%). See table below.

<b>Table 12. What was the main reason you stopped taking PrEP?</b>	<b>Percent of Patients Who Quit PrEP Program (N=48)</b>
I did not like the side effects	27.1%
I felt like I was not at risk for HIV	18.8%
Other* (see below)	18.8%
It was a hassle / inconvenient	10.4%
I kept forgetting to take my pills	8.3%
I did not have transportation to the clinic	8.3%
I was already taking too many other medicines	6.3%
I did not want people knowing I was taking it	2.1%
The clinic was closed when I could go there	0.0%
<b>TOTAL</b>	<b>100.0%</b>

\*Other: *“Aging [...] issues; Blood work was not coming back sufficient; Didn't have time to try and get to the clinic and meds were never ordered; It was difficult to make an appointment, never got called back from the clinic to schedule a visit for testing; Lot going on at the time to keep up; moved; Kream (sic) level was judged to be too high and the docs took me off PrEP; not free anymore; did not have health ins.”*

K. **Adherence counseling:** Respondents were asked whether a healthcare provider or navigator performed a series of adherence support activities. Most patients recalled that a provider talked with them about the importance of taking PrEP (92.3%). Fewer patients reported that a provider discussed how they could fit PrEP into their routine (79.5%) or asked the patient about what may make it difficult for them to take PrEP (60.3%). Only about 50% of patients said a provider suggested adherence tools or wrote an adherence plan for them. See the table below.

<b>Table 13. Did a healthcare provider (for example, a doctor or nurse) or navigator ever do any of the following?</b>	<b>Yes</b>	<b>No</b>	<b>Unsure</b>	<b>TOTAL</b>
Talk to you about the importance of taking PrEP every day?	92.3%	6.4%	1.3%	100.0%
Talk with you about ways to fit PrEP into your daily routine?	79.5%	15.4%	5.1%	100.0%
Ask you what may make it difficult for you to take PrEP?	60.3%	28.2%	11.5%	100.0%
Suggest tools, such as a Smartphone App or pill counter, to help taking PrEP easier for you?	50.0%	30.8%	19.2%	100.0%
Write down a plan to help you take PrEP every day?	46.2%	30.8%	23.1%	100.0%

L. **Clinical services:** Respondents were also asked a series of questions related to clinic experiences. More than three-quarters said “yes, definitely” to questions indicating they had positive clinical experiences during their most recent PrEP visit. Approximately 10% reported ‘somewhat’ or ‘not’ feeling their providers showed respect for them, 12% reported ‘somewhat’ or ‘not feeling’ their providers answered their questions/concerns in an understandable way, and 15% reported ‘somewhat’ or ‘not’ feeling like their information would be kept private. Slightly more than 20% reported ‘somewhat’ or ‘not’ feeling like the front desk staff treated them with kindness and respect. See Table 14 below.

<b>Table 14. Think about your most recent PrEP visit. Did any of the following things happen?</b>	<b>Yes - definitely</b>	<b>Yes - somewhat</b>	<b>No not really</b>	<b>MISSING</b>	<b>TOTAL</b>
Did the doctor or nurse show respect for you and what you had to say?	88.5%	9.0%	1.3%	1.3%	100.0%
Did the doctor or nurse answer your questions, or address your concerns, in a way you could understand?	85.9%	11.5%	1.3%	1.3%	100.0%
Did you feel that your personal information would be kept private?	83.3%	9.0%	6.4%	1.3%	100.0%
Did you meet with a PrEP Navigator?	82.1%	2.6%	14.1%	1.3%	100.0%
Did the front desk staff treat you with kindness and respect?	78.2%	19.2%	1.3%	1.3%	100.0%

M. **Factors that may affect PrEP adherence:** Patients were asked about a series of characteristics that may make adherence more challenging.

- a. Initial readiness to take PrEP: When asked how ready they were to initially take PrEP, 46.2% said they were somewhat ready and 10.3% said they were ‘not at all ready’. Fewer than half (43.6%) felt they were *very ready*.

- b. Perceived risk for HIV: More than 25% felt neutral (12.8%) or disagreed (14.1%) that they could have become infected with HIV prior to starting PrEP
- c. Perceived benefit of PrEP: While 78.2% of patients *strongly agreed* that PrEP could reduce their chance of getting HIV, 15.4% *agreed* and more than 5% felt neutral or disagreed.
- d. Psychosocial risk: One-third of patients reported a mental health condition. More than 10% reported experiencing intimate partner violence, homelessness and/or a substance use condition. Fewer than 5% reported a romantic or sexual partner disrupted their PrEP use.

<b>Table 15. Think about when you first heard about PrEP. How ready were you to take PrEP?</b>	<b>Percent</b>
Not at all ready	10.3%
Somewhat ready	46.2%
Very ready	43.6%

<b>Table 16. How much do you agree with these statements?</b>	Before I started taking PrEP, I could have become infected with HIV.	HIV can be a very serious disease.	Taking PrEP can reduce my chance of getting HIV.
Strongly agree	44.9%	97.4%	78.2%
Agree	28.2%	2.6%	15.4%
Neutral	12.8%	0.0%	3.8%
Disagree	6.4%	0.0%	1.3%
Strongly disagree	7.7%	0.0%	1.3%
TOTAL	100.0%	100.0%	100.0%

<b>Table 17. Do you have any of these challenges in your life?</b>	<b>Yes</b>	<b>No</b>	<b>MISSING</b>	<b>Total</b>
A mental health condition (for example, anxiety, depression, schizophrenia, bipolar disorder)	33.3%	65.4%	1.3%	100.0%
A substance use condition	11.5%	87.2%	1.3%	100.0%
Intimate partner abuse	10.3%	88.5%	1.3%	100.0%
Homelessness	10.3%	88.5%	1.3%	100.0%
Has a romantic or sexual partner ever thrown away your PrEP pills or discouraged your use of PrEP?	<5%	-	0.0%	100.0%
Has a romantic or sexual partner ever made you feel ashamed or embarrassed for taking PrEP?	<5%	-	0.0%	100.0%

**Patient comments:** Patients were asked three questions soliciting their feedback using open-comment boxes. Responses analyzed for key themes, explained below. Detailed comments are included as Attachment 1.

N. **Ideas to support adherence:** When asked, “What could we do to help you, and other PrEP patients, take PrEP every day?” 58.9% patients (n=46) provided a response. The leading

theme was to address the side effects (28.2%) by alleviating the side effects or educating people about what to expect. See table below. Full responses are in Appendix 1, Table A.

<b>Table 18. Themes from Comment Responses: What could we do to help you, and other PrEP patients, take PrEP every day?</b>	<b>N</b>	<b>% of Comments</b>
Address the side effects	13	28.2%
Give people adherence tools (like text reminders, an app, a pill box)	10	21.7%
Make sure that clinic services are accessible	8	17.4%
Continue to promote PrEP	7	15.2%
Other ideas	6	13.0%
Nothing else	2	4.3%
<b>TOTAL</b>	<b>46</b>	<b>100%</b>

- O. **Ideas to improve patients’ PrEP experience:** When asked, “What could the Virginia Department of Health staff do to improve your PrEP experience?”, 53.8% patients (n=42) provided a response. The leading theme was to improve clinic services by making them more accessible or of better quality (38.1%). Many patients gave positive feedback or complimented the program and staff (26.2%). See table below. Full responses are in Appendix 1, Table B.

<b>Table 19. Themes: (Comments) What could the Virginia Department of Health staff do to improve your PrEP experience?</b>	<b>N</b>	<b>% of Comments</b>
More accessible / better quality clinic services (ex. Hours, wait times)	16	38.1%
Positive feedback / Complimented the program	11	26.2%
Address the side effects	6	14.3%
More advertisement	3	7.1%
Expand PrEP to other areas	2	4.8%
Other – No clear theme	4	9.5%
Address cost issues	2	4.8%
<b>TOTAL</b>	<b>42</b>	<b>100%</b>

- P. **Anything else?** Respondents were asked “Is there anything else you would like to tell us?” These responses were not themed but are included in the Appendix, Table C.

## V. Findings and Recommendations

Findings and recommendations are organized in the following four categories: 1) Learning about and deciding to seek PrEP; 2) Adherence levels and counseling; 3) Barriers to medication adherence and program retention; and 4) Program planning and support.

### 1. Learning about PrEP and Deciding to Seek PrEP

Patients cited healthcare providers as the leading way they first heard about PrEP (33.3%) and a leading way patients ever heard about PrEP (59.0%). Healthcare providers were leading influence in patients' decision to learn more about PrEP (62.8%) and in patients' decision to try to get on PrEP (52.6%). *NOTE: While the term 'healthcare providers' was used in the survey and specified as "for example, a doctor or nurse," patients may have thought that navigators or DIS workers were doctors or nurses and included them in their response as such. So 'healthcare provider' in this situation should not necessarily be limited to doctors and nurses.*

- **Recommendation: Continue to support the important, influential role of healthcare providers.** Assure that doctors, nurses and other healthcare providers, including navigators and DIS workers, have the information and tools they need to promote and support PrEP services. In addition, assure they have educational resources on hand to give patients. Offer continuing education opportunities for new providers to offer PrEP and for experienced PrEP providers so they can offer optimal PrEP services.
- **Recommendation: Support PrEP providers so they can offer optimal PrEP adherence counseling services.** Offer training opportunities, tools and other strategies to help providers support PrEP medication adherence.

Patients also cited advertisements (for example, on social media, TV, radio, bus or billboard) as an important way that they first heard about PrEP (20.5%) or ever heard about PrEP (59.0%). 21.8% of patients said that advertisements helped them decide to learn more about PrEP and 16.7% of patients said that advertisements helped them decide to try to get on PrEP. Fewer than 5% cited advertisements as the single greatest reason they decided to try to get on PrEP.

- **Recommendation: Continue to promote PrEP using a variety of media sources.** Advertisements are important way that people learn about PrEP and are influential in helping people along the PrEP decision making process.

Patients also cited friends and romantic partners as significant influencers in helping them first hear about PrEP (20.5% and 11.5% respectively), ever hear about PrEP (44.9%, 34.6%), and helping them decide to learn more about PrEP (30.8%, 21.8%). Friends and romantic partners were influential for 15.4% and 21.8% of patients, respectively, in their decision to try to get on PrEP. Fewer than 10% cited the influence of friends or romantic partner as cited as the single greatest reason they decided to try to get on PrEP.

- **Recommendation: Engage friends and romantic partners in adherence counseling strategies.** Utilizing strategies such as identifying a support person, couples counseling and buddy systems may help some PrEP patients stay in the program and/or adhere to

their medication. Similar strategies have shown to be effective in HIV treatment adherence programs.

- **Recommendation: Include friends and romantic partners in the audience for media promotions.** To date, PrEP advertisements have mainly focused on promoting PrEP to potential users. However, including messages directed at friends and romantic partners is a potential opportunity to increase the reach and influence.

The top three reasons (unduplicated) that patients decided to try to get on PrEP were to feel more protected (51.3%), being encouraged by a healthcare provider (12.8%) and knowing somebody with HIV (10.3%). For 60.3% of PrEP patients, wanting to feel more protected was the leading factor among other factors.

- **Recommendation: Support patients' need to feel that PrEP is protecting them.** Emphasize PrEP's protective qualities at the beginning and throughout patient's participation. Utilize plain language and techniques to assure patient understanding.

## 2. Adherence Levels and Adherence Counseling

One-quarter of current PrEP patients reported missing at least one day of PrEP in the past month, meaning three-quarters (75%) did not. Only 10% reported missing one or more pills in the past 7 days or, conversely, 90% reported being adherent. Most patients feel confident they can continue to take PrEP but 13.3% are only somewhat confident, indicating potential risk for dropping out. However, this is based on a small sample (n=30).

- **Recommendation: Explore and implement strategies to help improve adherence for the 10-25% of patients who struggle.** See below for additional recommendations related to this.
- **Recommendation: Consider collecting additional data to confirm adherence rates.** These data are based on 30 patients and may not be representative. The PrEP program should consider collecting additional medication adherence data from current patients.

Patients recalled providers offering varying levels of adherence counseling and strategies. Most patients recalled that a provider talked with them about the importance of taking PrEP daily, as prescribed (92.3%). Fewer patients reported that a provider discussed how they could fit PrEP into their routine (79.5%) or asked the patient about what may make it difficult for them to take PrEP (60.3%). Only about 50% of patients said a provider suggested adherence tools or wrote an adherence plan for them.

- **Recommendation: Routinize adherence counseling.** PrEP program staff should assess and provide counseling about adherence at each encounter. Counseling should include discussing with the patient what their barriers to adherence could be, including psychosocial factors and stigma. Adherence counseling should also include helping patient identify how to fit PrEP into their daily routine and writing down a plan. Consider adopting a standard tool for assessing and providing adherence counseling across sites.

- **Recommendation: Offer tools for all patients to help them remember to take their PrEP.** Easy strategies are to give all patients a pill box at the first visit and a list of mobile apps or home devices (like alarms and cues) they can use to help them remember to take their pills. Navigators should check in with the patient at each encounter to see if the tool helps them to remember. If a tool is not working for a patient, offer another one or work with the patient to identify reminder strategies.

More than one-third (35.9%) of PrEP patients reporting cycling on and off PrEP (at least 14 days of not using it); leading reasons were forgetting to take PrEP and barriers to clinic services. Fourteen percent of patients reported filling a prescription but not taking any of it (full-bottle non-adherence), with the leading reason being not feeling at risk for HIV. Each of these barriers were important themes and are discussed further below.

### 3. Barriers to Medication Adherence and Program Retention

Patients cited PrEP's negative side effects as a leading barrier to adherence and retention throughout the survey. Side effects were the top cited challenge that made it hard for patients to take PrEP (44% patients) and the leading reason patients quit the VDH PrEP program (27%). The leading theme in the patient comments was 'side effects'; patients felt VDH should better address the side effects by figuring out how to alleviate them or letting patients know ahead of time what to expect. Side effects were not a major reason for cycling on-and-off or full-bottle non-adherence.

- **Recommendation: Address side effects of PrEP early and often.** Incorporate patient education on side effects from the beginning. One easy way is to develop and give all patients a handout on what side effects they may experience, steps they can take to try to alleviate them at home, and when to call their provider. Providers, including navigators, should assess for side effects at each visit and offer practical solutions. As new PrEP medications become available, providers should assess whether a different medication is a better option for the patient.

Forgetting to take PrEP was also a leading theme. It was the second leading issue that ever made it hard for patients to take PrEP (29.5%) and was the leading reason that patients cycled on and off PrEP (21.4%). The second most common theme in the patient suggestions for improving adherence was providing adherence tools like pill boxes and reminder apps. However, only 50% of patients said that a healthcare provider or navigator had given them a tool like this to help them remember. This is an important area of opportunity.

- **Recommendation: Offer tools for all patients to help them remember to take their PrEP.** This is a repeat of a previous recommendation; see above for more details.

Patients reported psychosocial issues that pose challenges to adherence and retention. Stigma was cited by nearly 20% of patients as something that ever made it hard for them to take PrEP, though it was not a leading reason for people quitting PrEP (<10%). In addition, one-third (33.3%) of patients reported having a mental health condition and more than 10% self-reported experiencing intimate partner violence, homelessness and/or a substance use condition. Fewer than 5% reported that a romantic or sexual partner disrupted their PrEP use.

- **Recommendation: Assess PrEP patients for psychosocial risks including mental health, homelessness, intimate partner violence, substance abuse and stigma.** Use an assessment tool and techniques such as motivational interviewing and service navigation to connect PrEP patients to resources to help address issues that are identified.

Barriers accessing clinical care was another theme throughout the survey. More than 10% of patients cited logistical access barriers as something that ever made it hard for them to take PrEP – such as lack of transportation, the clinic being closed when they could get there, or running out of pills before they had a new bottle. Ten percent of patients who cycled on and off PrEP listed one of these as the main reason. A number of patient comments also spoke to these types of barriers, many with a high degree of apparent frustration.

- **Recommendation: Improve accessibility and availability of services.** Clinics should help patients secure transportation if necessary and offer more flexible hours. In addition, clinics should take measures to proactively ensure that medication refills occur when patients need them, remind patients of clinic appointments and medication pickups. Offer delivery options to patients if it available and appropriate.

Patients feeling like they were not at risk for HIV, and having doubts about their readiness for PrEP, was also an important theme. Fourteen percent of PrEP patients felt like they were not at risk for HIV prior to taking PrEP and 12.8% had a neutral opinion about this. In addition, 43.6% of patients said they were ‘very ready to take PrEP’ when they first heard about it, with 10.3% feeling not ready and 46.2% feeling only somewhat ready.

**One in four new PrEP patients had doubts that they were at risk for HIV and more than half felt only somewhat or not ready for PrEP.** If a person has low readiness for PrEP and perceive themselves at low risk for HIV, this could reduce their chances of staying in the PrEP program, even if they have a PrEP indication, especially if they encounter other barriers along the way.

In addition, feeling not at risk for HIV was the second leading reason that patients quit PrEP (18.8%). Feeling not at risk for HIV was also the third top challenge that made it hard for patients to take PrEP. While this was true for 13.3% of current patients, the rate was more than double (33.3%) for previous patients, which makes sense given it was a leading reason for quitting PrEP.

- **Recommendation: Develop and utilize a PrEP readiness tool that a provider or navigator could use with a patient at the beginning of the process.** This would provide an opportunity to have a conversation about the patient’s thoughts and feelings and help inform patient decision making. Patients who decide they are not ready yet can be contacted at follow up intervals to re-assess readiness.
- **Recommendation: Check on the alignment between patient perceived risk for HIV and indication for PrEP.** The PrEP program should assure there is a clear indication for the patient being on PrEP and assess the patient’s readiness for PrEP including their perceived risk for HIV. These elements should be assessed throughout the patient’s participation in the program.

- **Recommendation: Check on patients often, especially at the beginning.** This would be especially important for patients who were unsure about their need or readiness for PrEP, and also provide an opportunity to assess for side effects, forgetfulness and see how they were doing overall. One patient suggested more frequent contact, such as every two weeks.
- **Recommendation: On future surveys, ask about reasons a patient may feel they are not at risk for HIV.** This survey provided an option of “I did not feel at risk for HIV” as a reason for stopping PrEP or making it hard to take PrEP, but did not ask why they felt not at risk. Next time the survey should include a question about why they did not feel they were at risk for HIV.

### **Program Planning and Support**

When patients were asked about their experience in the clinic, most clients felt the provider *definitely* showed respect for them and what they had to say (88.5%) and answered their questions and concerns in a way they could understand (85.9%). However, 10-12% reported ‘somewhat’ or ‘not’ feeling their providers showed respect for them or answered their questions/concerns in an understandable way; 15.4% of patients reported ‘somewhat’ or ‘not’ feeling like their information would be kept private, and 20.5% reported ‘somewhat’ or ‘not’ feeling like the front desk staff treated them with kindness and respect.

- **Recommendation: Assess patient satisfaction and improve customer service.** It is important that patients feel listened to and heard, get their questions and concerns answered in a way they can understand, feel confident that their information will be kept private and they are treated with kindness and respect by all staff. Efforts to assess and improve these aspects of patient care will help promote PrEP retention.

Finally, when supplemented from program data, a story emerges that tell us that PrEP patients may be more likely to drop out of the program than to be non-adherent to their medication. Data from this survey indicate that between 10-25% of patients report some recent non-adherence to their medication, while over 50% of PrEP initiators have dropped out of the program.

- **Recommendations: Treat and explain PrEP more like a program than a pill. Focus on supportive strategies to help promote daily adherence and retention in the program.** In order to focus on retention, patients need to understand from the beginning that they are committing to a daily pill and regular visits, and what that may entail for them.
- **Recommendation: Provide staffing and resources to help support medication adherence and program retention.** The PrEP program needs to be appropriately staffed to provide all of the support described in this report – PrEP advertisements, provider education, psychosocial screening and referral, adherence counseling, and frequent follow up for patients at risk for quitting the program.

## VI. Conclusion

The full benefits of PrEP as an HIV prevention tool as administered by the Virginia Department of Health can only be realized if the program is able to effectively recruit and retain patients most in need of the program and support patients' medication adherence. This report is based on analysis of a survey completed with previous and current PrEP patients, and presents an opportunity to incorporate the patient voice as the program moves forward with planning strategies to support medication adherence and program retention. The findings and recommendations can help inform short-term and longer-term planning activities to help maximize the impact of the program.

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## Appendix 1. Patient Comments by Category

<b>A. “What could we do to help you, and other PrEP patients, take PrEP every day?”</b> <i>Spelling and grammar errors were not corrected to reflect true nature of comments.</i>
<b>THEME: Address the side effects</b>
1. Work on the side effects of the pills, please!!!
2. Call and check on people taking prep every two weeks especially if there are unpleasant side effects.
3. eliminate side effects
4. Get rid of the horrible side effects.
5. Help us find a way to deal with the side effects
6. Is the icky feeling going to go away? Provide more information about the side effects - it goes from one feeling to the next and it's not a good feeling. It conflicts with the one-a-day.
7. It causes rapid weight gain in some people, I've learned, and this was not explained to me as a possibility when I began the process.
8. Let them know of the long term side effects
9. Make its ingredients so I can take it without killing my kidneys
10. maybe give us something to help with the side effects
11. Put emphasis that the side effects are something to be warn about.
12. Stop the nausea it was more than I could bear
13. Try and figure out the side effects and make them more comfortable
<b>THEME: Continue to promote PrEP</b>
14. run ads in magazines,news papers,send out txt messages put out flyers at jobs schools,colleges
15. Continue to promote
16. Just continue to press the importance
17. Keep advertisements going people will listen hopefully.I would like too be on prep again in the future.
18. Keep the information out on public information platforms, just keep it out there.
19. Give them the knowledge about prep
20. Honestly just continue to put the information out there and being well informed
<b>THEME: Give people adherence tools (like text reminders, an app, a pill box)</b>
21. Reminder on prep visits
22. App/pill taker
23. Give us a free pill minder at our first appointment maybe
24. have a open mind and heart be a good dog and listen and learn
25. I don't remember if you send appointment text reminders or not, but that could be helpful. My aides were very helpful with making sure I had my bloodwork in order and was ready to receive my medication.
26. i just take it when i take my vitamins so its easy to remember already
27. I like the idea of an app to help remind me
28. Maybe send a reminder out to peoples phones

29. Put the pills next to your car keys and take it in the am before u leave
30. Remind us and check up on us more
<b>THEME: Make sure that clinic services are accessible</b>
31. Provide a free health clinic for prep in [...]
32. Broader Availability (pharmacies)
33. I don't have a car so transportation was a big deal. There were times when I got to the clinic that they were closed for a meeting or lunch or some other reason. If you say that my pills are ready, I should be able to pick them up during your operating hours.
34. Im not really sure the appointments were the most difficult for me missing work.
35. Increase hours available to pick up prescription
36. Make getting refills less of a hassle as well as trying to get the dates for testing sorted.
37. Make it a lot more easier to get PrEP. Just give us one number so we can call and we can order the prep. Most of the times, I'll be referred to one person, then I have to go to another line, that's very annoying. That's how HIV will stay relevant because people don't want to go through four lines before we talk to someone.
38. Make it more available and easier to access appointments
<b>THEME: Other</b>
39. Show the importance of takn prep show the importance of prep
40. IF the pill was smaller
41. Make the meds safer.
42. Put pressure on the pharmaceutical company to release affordable prep with less toxic side effects
43. Show the effects that HIV has and how it can hurt you.
44. Highlight the positives
45. Make it available to the community.

<b>B. What could the Virginia Department of Health staff do to improve your PrEP experience?</b> <i>Spelling and grammar errors were not corrected to reflect true nature of comments.</i>
<b>Address the side effects</b>
1. Explain all known side effects at the outset
2. Help us find a way to deal with the side effects
3. Lessen the side effects
4. Prepare patients more for the side effects- mine were terrible, and did not ever go away
5. Stop the side affects
6. They need to tell people it might shut down your kidneys
<b>Complimented program</b>
7. [...] and her team are the best
8. I had nothing but a great experience with every single person I came into contact with, you have a good team.
9. I think the program is excellent and can't think of recommendations for improvement.

10. I think VDH is doing a good job so far I just feel like i don't need it anymore though my romance life has kinda been nonexistent
11. It was a very positive one. I don't have anything bad to say!
12. its already ok
13. My experience is always great
14. Nothing every single time I have gone in everyone has been very informative and helpful and knowledgeable
15. Nothing everyone was very nice and helped explain all the risks.
16. The staff was very helpful.
<b>Expand PrEP to other areas</b>
17. I would like for all health departments in each county to offer PREP. I had to stop because I left [...] which meant a long drive each month to continue my prep. The health department in the county that I was in [...] didn't participate and had no idea about the prep program.
18. It would be nice if you could mail the prescription to me or open an office in Virginia Beach for me to get the prescription filled.
<b>Address cost issues</b>
19. Ensure prep is free
20. make it easier for people who cannot afford ins. to get prep as it is i do not make enough money to pay for a decent ins. and am self employed and make a small amount above the cut off
<b>More accessible / better quality clinic services (ex. Hours, wait times)</b>
21. Being more polite and discreet
22. Biweekly phone calls. Clinic hours should be later in the evening to better accommodate people who between the hours of 9-5. There should be access to prep clinics on Saturdays for those people who cannot get into the clinic during the week and during the hours of 9-5. I suggest Saturday prep clinics from 9-1.
23. Discussion is always the best method, there needs to be more honest and upfront information provided
24. extend appointment hours for people who work pass there closing time
25. Faster appointments
26. Have a seminar, be honest; once you test people and they come back, negative or positive; there should be groups for 'negatives and positives' separately - different people need to know how to protect themselves. We're all fighting to stay healthy.
27. Increase hours available to pick up prescription
28. Just make scheduling appointments and getting refills flow better.
29. Make more pickup locations or times
30. Make the clinical staff make sure they are ordering and having meds in stock prior to you running out.
31. Maybe have a day when you r open later
32. More privacy
33. not treat me like a test subject, not be ridiculous in needing to ask if i could take OTC drugs...PREP has been out for many years...drug interactions should be well known by

now. way too many probing questions about my sexuality and sex practices which are no one's business. Too much of a waste of time to pick up the pills every month. Pills should be mail order...if you want to test for HIV every 6 months, that would be fine. The ridiculous amount of testing done was a big turn off.
34. provide clinics open later
35. More in-depth counseling
36. Stop making drive just to pick up meds. Was told it'll be mailed after my 2nd testing or bottle.
<b>More advertisement</b>
37. Advertise, educate, and more accessible to the Virginia residents.
38. More advertisement
39. more advertising
<b>Other</b>
40. I don't know if there's much you can do. Some doctors are very comfortable with talking about it, others will look at you dead in the face like they don't know what you're saying or if you're from another planet.
41. Provide ways to help explain patient use of prep to others without freaking them out like you have HIV.
42. Broaden knowledge among PCPs
43. 60 day supply
44. Put more people on prep

<b>C. Is there anything else you would like to tell us?</b>
<i>Spelling and grammar errors were not corrected to reflect true nature of comments.</i>
1. been with same partner for a year and I been on prep as safety net since I had multiple partners in the past
2. I am glad this program exists
3. I believe prep is a good pull for those that can tolerate it. I recommend it to all my friends.
4. I felt so sick for 2 months. It really messed me up physically and mentally. It caused me to not be able to do my job. Very slowly I got back to normal, but not before having to deal with adrenal fatigue and anxiety that were a direct result of taking the medication.
5. I may return to the program when [...] are somewhat resolved.
6. I need housing assistance ASAP. I have a job
7. [...] I recently stopped using the health department though I still strongly encourage others to. It was very hard to find a primary care doctor who was familiar with PREP however and I was asked numerous times if I had HIV and that's why I wanted it. Ugh. The more education to primary care doctors the better.
8. I thankfully had no side effects so I might take it again. I'm currently a [...] and have a bad habit of forgetting to take care of myself. That's not your fault.
9. I'm glad there is a Prep Program. I had sex with [...]. Trying to get the pills right after that was very expensive.

10. It would be good if the program were extended to the VA Beach Dept. of Health so that travel to Norfolk were not necessary
11. Keep up the good work
12. Look into safer alternative like a shot once per month of some sort.
13. Major side effects of PreP
14. My aides were very helpful and I had a positive experience!
15. My only recommendation, for most places, just give us one number that we can talk to and order the PrEP, once you start giving one or two lines, that's when I'll never call back. Unfortunately, if you're going to get it for free, the process is even more complicated, I would know. But once you get insurance is easier, but even then they want to refer you to so many lines.