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Why do HIV PrEP Patients Become Lost-to-Care and How Can We Improve PrEP Retention?

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ABSTRACT

Objectives
To assess reasons for patients being lost-to-care (LTC) at an urban health center (Philadelphia, PA, USA) that provides access to oral tenofovir/emtricitabine(TDF/FTC) as pre- exposure prophylaxis(PrEP) to patients ages 13-30 years through a drop-in model of care.

Methods
Ninety-nine patients were identified as LTC based on not visiting a clinician in ≥4 months during the period April 2016-January 2017. Patients were contacted by phone/email to participate in a voluntary telephone survey regarding reasons for falling out of care. Results were analyzed descriptively.

Results
Of the 99 patients preliminarily identified as LTC, 19 completed the survey. Reason(s) for becoming LTC included: 47%(9) relocation, 11%(2) transportation difficulties to/from clinic, 26%(5) financial/insurance problems, 5%(1) perceived medication side effects, 16%(3) trouble remembering to attend appointments regularly, 5%(1) difficulty with daily medication adherence, and 0% social stigma. Furthermore, 21%(4) remain at high-risk of HIV/STI acquisition after becoming LTC. The main study limitations are selection bias and small sample size, where the small sample size did not allow for statistical significance.

Conclusion
While the major cause for becoming LTC was relocation, these findings suggest 37% of LTC incidences may be preventable with additional/up-front support. Because 21% of LTC patients remain at high-risk of HIV/STI acquisition, proactive re-engagement initiatives are potentially useful.

Keywords
HIV/AIDS; Pre-exposure prophylaxis; Retention and care; Socioeconomic factors; Adolescent Health; Lesbian/Gay/Bisexual/Transgender Persons.

INTRODUCTION

In July 2012, the US Food and Drug Administration (FDA) approved oral tenofovir/emtricitabine (TDF/FTC, or Truvada™) as pre-exposure prophylaxis (PrEP) for individuals at high-risk of contracting human immunodeficiency virus (HIV), marking an important step toward the 90:90:90 initiative.[1] Currently, PrEP is being prescribed in urban areas of 23 states and Washington, DC, USA.[2] Because of its efficacy in preventing the spread of HIV, PrEP has great potential to be a public health tool for the medically underserved.[3] To move toward ending the epidemic, determining the best model to deliver HIV PrEP to high-risk populations is

critical, and many scholars have examined the most effective way to deliver PrEP to large populations.

Thus far, the importance of creating socially and culturally competent programs that incorporate PrEP into HIV and sexually transmitted infection (STI) prevention services in clinics and primary care services has been established.[4] While some believe a traditional primary care setting is the most feasible venue for PrEP care,[5] many healthcare providers are enthusiastic about PrEP being prescribed in a larger variety of clinical and public health settings that serve high-risk patients such as harm-reduction programs (i.e. needle exchange programs), STI clinics, and mobile vans that provide HIV testing and other preventive health services.[6] Furthermore, STI clinics have been found to initiate and retain more clients in PrEP care compared to a large health maintenance organization (HMO) and HIV-specific reproductive health programs.[7] One of the reasons that STI clinics may be so effective in providing PrEP is because they provide short-term, immediate care on a drop-in basis, which can include services such as same-day PrEP initiation.

Despite the benefits drop-in models may provide to PrEP care, aspects of the drop-in clinic model have also been identified as potential reasons for patients being lost-to-follow-up (LTF). For example, there is the perceived concern about suboptimal retention in care due to regular follow-up with patients not being standard in some drop-in model structures.[4] Additionally, these programs may have limited resources, and many do not have the capacity to provide broader social services necessary to address the multiple needs of an at-risk population.[8]

Furthermore, previous studies on PrEP care in urban men who have sex with men (MSM) patients have identified issues at every level of care that could result in LTF, including inability to afford medication, lack of transportation to medical facilities, medical side effect intolerance, problematic dosing schedules, decreased risk perception, and lack of time.[9] Stigma has also been cited as an added barrier to PrEP access, specifically stigma from peers or providers who believe PrEP care may lead to riskier behavior and diversion of resources away from HIV-positive people,[7] from parents who may be unsupportive, from religious communities, or from partners who may view PrEP as lack of trust.[10]

In 2013, our clinic, housed within an urban, community health and drop-in center in Philadelphia, Pennsylvania, USA began the "I Am Men's Health" Program, which provides access to oral PrEP among several other HIV prevention and primary care services to high-risk, low-income youth (ages 13-30 years) who are predominantly African-American men who have sex with men (MSM) and transgender women (TGW) who have sex with men. This program utilizes a drop-in model of care and is the largest program of its kind in Philadelphia focusing on preventing HIV seroconversion in this high-risk group. However, while the clinic focuses on PrEP and allots several hours each day to walk-in care, the clinic aims to help patients navigate the healthcare system and to increase their overall access to healthcare. Therefore, patients are actively encouraged to schedule new and follow-up appointments for preventive medicine, primary care, and social services as well.

Studies on PrEP implementation are still in their infancy with much of the programmatic literature focusing on planning for roll-out, and only recently have studies begun to look at PrEP retention[10,11] and causes for loss to care.[10] However, to our knowledge, there has yet to be a study that evaluates retention and causes for loss to care in a PrEP program that utilizes a drop-in model of care. The purpose of the current study is to address the knowledge gap regarding real-life challenges in PrEP program implementation in urban areas of the United States, specifically with regards to a program that utilizes a drop-in model of care. The present study aims to: 1) evaluate reasons for patients becoming lost-to-care (LTC) (i.e. relocations, medical side effects, stigma, logistical concerns, etc.), 2) assess the patient experience of a modified drop-in model of care, and 3) assess ongoing risk factors for HIV-1 seroconversion in patients who are LTC. Results of this study may suggest modifications or improvements that can be made to PrEP care delivery models.

METHODS

Study Population

Young adult (18+) patients within this clinic's electronic medical record (EMR) who had not attended a PrEP or primary care visit in ≥4 months were defined as LTC and contacted to participate in a voluntary telephone survey that assessed several factors hypothesized to affect retention based on previous studies.[4,7-10] All parts of the survey were optional. Minors, non-english speaking patients, patients with no documented contact information in the EMR system, patients who were currently incarcerated, and patients who had documentation of transitioning care to another clinical center were excluded. Informed consent was obtained verbally from all subjects prior to administering the survey. This study was approved by the Institutional Review Board at Philadelphia FIGHT.

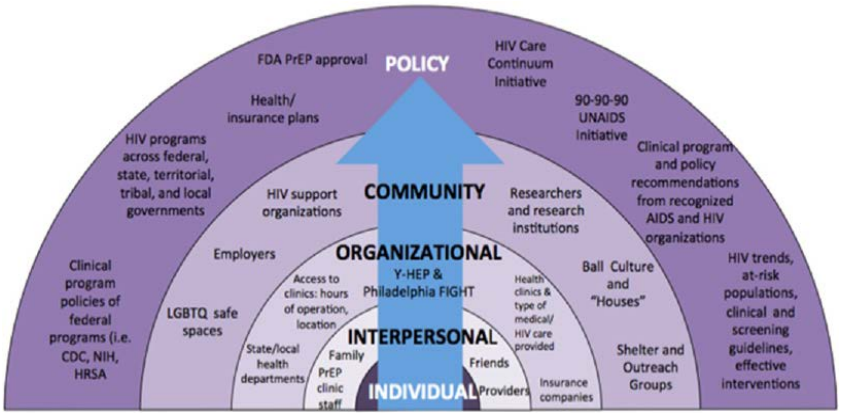
Development of Survey Tool

The survey was developed using the social-ecological model of health behavior (Figure 1).[12,13] The questions were based on validated survey tools, including the Consumer Assessment of Healthcare Providers and Systems survey,[14] and were broken into sections to reflect the various individual, interpersonal, organizational, and societal factors that affect retention of PrEP patients in care (Appendixes A and B).

Data Analysis

Survey data were entered into a password-protected database (REDCap). Descriptive statistics were performed through REDCap and Microsoft Excel. Composite scores for each question with numeric responses were calculated to provide a quantitative measure of patients' responses. Means and standard deviations were calculated around each composite score.

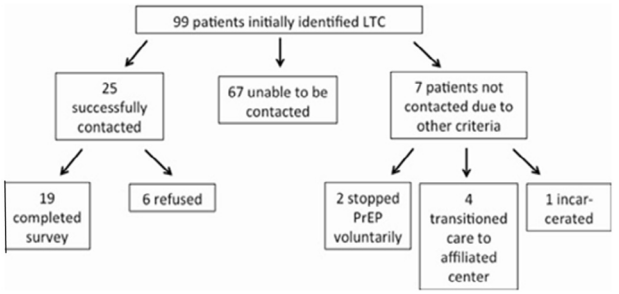
Figure 1. *Social-ecological Model of Health for PrEP and HIV care (Adapted from CDC)*[22]



RESULTS

Patients were contacted over a 10-month period, April 2016 to January 2017. Of the 99 patients initially identified as LTC, 19.2% (19) completed the survey, 67.7% (67) could not be contacted, 6.1% (6) refused, 4.0% (4) had transitioned care to an affiliated clinical center, 2.0% (2) stopped PrEP voluntarily, and 1.0% (1) was incarcerated and therefore not contacted (Figure 2). Of the 19 patients who completed at least a portion of the survey, 10 were not interested in re-enrolling in PrEP care, 5 were interested in re-enrolling into the PrEP program and 2 did, in fact, re-enroll. Therefore, out of 99 total LTC patients, 2% (2) re-enrolled.

Figure 2. *Flow Chart Showing How Patients Responded to Contact*



Out of the 19 survey respondents, 47% (9) reported coming to the clinic for primary care and PrEP services, while 54% (10) reported coming solely for PrEP. 26% (5) of respondents did not return after receiving their first PrEP prescription, 2 of whom were receiving primary care at the clinic while 3 of whom received no services other than PrEP. Of the remaining 14 respondents, the average time on PrEP before becoming LTC was 7.29-months (range of 1 to 32-months).

Clinic and PrEP Access (Relocation, Transportation, Finance)

All 19 survey respondents answered this section. They reported the following regarding access to the PrEP clinic: 47% (9) moved out of the area (relocation), 11% (2) were unable to get transportation on a regular basis (i.e. lack of cab/public transit fare), 26% (5) experienced financial/insurance problems (i.e. losing insurance, being unable to afford copays, PrEP was too expensive for them), and 26% (5) were unable to get time off work. Of note, those who stated relocation as their reason for becoming LTC, had all moved for work or school purposes.

Social Stigma/Support

Seventy-nine percent (15) of respondents answered questions related to social stigma. 0% reported feeling pressure to stop PrEP or experiencing judgment from family, intimate partner(s), or peers. Similarly, 0% felt their personal or religious beliefs conflicted with taking PrEP. Therefore overall, 0% felt stigma was a barrier to their PrEP care.

Other Reasons Described by Respondents

Sixteen percent (3) of respondents cited trouble remembering to come to appointments on a regular basis. 5% (1) became LTC due to perceived medication side effects (sexual arousal). 5% (1) found taking the pill every day to be difficult (this patient also noted that they were working three jobs at the time). 5% (1) stated that they were in a monogamous relationship, therefore taking PrEP no longer seemed "worth it".

Table 1. *Patient Responses: "Have Any of the Following Reasons Affected Your Desire or Ability to Come to the Clinic Regularly?"*

Reason	Number (%) Responding "Yes"
I moved out of the Philadelphia area	9 (47.4)
I was unable to get transportation	2 (10.5)
I do not like coming to [the clinic]	2 (10.5)
I had trouble remembering to come to [the clinic]	3 (15.8)
Taking my pill every day was difficult	1 (5.3)
I did not like the side-effects I felt after taking PrEP	1 (5.3)
I was unable to get time off of work	5 (26.3)
I thought PrEP was too expensive or I was frustrated by insurance	5 (26.3)

Clinic Experience

Seventy-four percent (14) of respondents answered questions related to their experience at the clinic. This section of the survey had the following response options: 4–always, 3–usually, 2–sometimes, 1–never. Questions and response averages can be found in Tables 1 and 2. Averages for each question are not statistically significant from one another.

Table 2. *Averages for Survey Questions about Patient Experience at the Clinic*

Question	Response Average±Standard Deviation
How often were medical staff courteous?	3.93±0.27
How often did clinicians treat you with courtesy and respect during your appointment?	3.93±0.27
How often did clinicians listen?	3.86±0.36
How often were you easily able to schedule an appointment?	3.23±1.17
How often was PrEP care explained in a way that was easy to understand?	3.79±0.58
How often were you seen in a reasonable amount of time for a walk-in appointment?	3.54±0.52

Patients Remaining at Risk of HIV Acquisition

Seventy-nine percent (15) of respondents answered survey questions related to ongoing HIV risk (Table 3). Of these, 6.7% (1) endorsed being diagnosed with an STI since becoming LTC and 13% (2) believed they might have been exposed to HIV since their last PrEP visit. 73% (11) reported that PrEP did not cause them to have riskier sex, while the rest reported they had or would consider taking greater risks since starting PrEP. 5% (1) specified that the medication made it seem that they had an extra safety net, thus they would contemplate riskier behavior "but not necessarily act on it."

Table 3. *Patient Reported Stigma, Conflicting Beliefs, and Sexual Risk (n=15)*

Question	Number (%) Responding "Yes"
Did you feel pressure to stop PrEP or judgment from family, intimate partner(s), or peers?	0 (0)
Do your personal or religious beliefs conflict with taking PrEP?	0 (0)
Did you feel taking PrEP caused you to have riskier sex than you did before you started taking PrEP?	4 (26.7)
Have you been diagnosed with a sexually transmitted disease in the last 3 months?	1 (6.7)
Do you have any reason to believe you might have been exposed to HIV in the last 3 months?	3 (20)
Are you interested in finding out how you might re-enroll in [PrEP]?	5 (33.3)

DISCUSSION

Re-engagement and retention in HIV care are important for ending the HIV epidemic, as 61% of new HIV infections arise from "persons who are not adequately retained in care".[15] Because our results demonstrated that at least 19% of PrEP patients who are LTC are still at-risk for HIV, retention in PrEP care is similarly important to ensure that more people do not become infected. Because retention in care is known to improve health outcomes, a focus on retention in PrEP care for underserved urban populations may also decrease health disparities.[16,17] Public health entities that regulate funding and make recommendations for programs that provide PrEP may be informed by this and other studies. In addition, foundations and other organizations that support advancing health for adolescents/young adults, urban youth, and/or groups at high risk of HIV acquisition, may look to fund initiatives for community-based organizations that address these barriers to care.

In order to evaluate and improve retention in PrEP care, we aimed to understand why patients became LTC. While becoming LTC did not seem to be affected by the specific health care delivery model of the clinic, our finding that the most commonly experienced barriers to PrEP retention were due to issues with clinic access (i.e., relocation, transportation, medical costs) suggests that more resources may be needed to accompany PrEP-prescribing programs for urban youth and young adults. Transportation issues, financial/insurance issues, and problems attending appointments due to work have been noted to be barriers to care in other studies for patients who struggle to maintain their PrEP care, including urban MSM patients.[7,9]

Our study found that 37% of LTC incidences could have been prevented with additional/up-front support, such as proactive transportation assistance or education on insurance loss not prohibiting PrEP care, and that at least 21% of LTC patients remain at high-risk of HIV and STI acquisition. These solutions are not limited to benefitting PrEP programs, but may also be useful for clinics that provide HIV care and primary care services to populations at high-risk for acquiring HIV, and could include greater financial support for provisions such as up-front vouchers/tokens for local transportation, a greater emphasis on how to continue care if health insurance is lost, and additional written or online educational resources related to PrEP and HIV healthcare at the first visit. Furthermore, because a significant proportion of LTC patients remain at high-risk of HIV acquisition, proactive re-engagement initiatives, such as periodic attempts to contact LTC patients, are potentially useful. This is recommended by the International Association of Providers of AIDS Care (IAPAC)[18] and has been shown to re-engage a significant proportion of patients to HIV care.[19]

Three participants had trouble remembering to come to appointments regularly and 1 had trouble remembering to take their pill regularly. This suggests a role for implementing/expanding reminders prior to appointments in the form of emails, text messages, or phone calls–this has been studied in several populations[20] but has not been studied in urban young adults taking PrEP (a group at particularly high risk of HIV acquisition). The IAPAC also recommends approaches such as this for optimizing the HIV care continuum, and additional studies have shown that increased personal contact increases visit adherence.[17,21] For patients who have trouble remembering to take PrEP regularly, programs might

consider providing small devices, such as a medication keychain (which this site recently began providing to patients), that can serve as reminders in accordance with IAPAC recommendations.[18]

This study may have been limited by selection bias, as subjects who agreed to participate in the study may have reported a different array of barriers than those we could not reach. Additionally, this study has a small sample size. Of the 99 patients initially identified as LTC, only 25 were successfully contacted, only 19 completed the survey, and lack of information on the patients we could not contact may skew our results. The small sample size also did not allow for statistical analyses of significance or effect size.

This in itself has policy ramifications, as the difficulty with re-engagement despite a robust dedicated effort suggests that re-engagement efforts for patients taking PrEP for HIV prevention likely need to be done much earlier and ideally before patients are lost to care. An additional limitation of the study is generalizability, as the results may not be generalizable to other PrEP clinics that are unable to provide care to uninsured patients, clinics in other geographic settings, or clinics with other patient populations.

CONCLUSION

Our findings suggest several LTC incidences could have been prevented with additional/up-front support from the provider organization for problems such as transportation, finances/insurance, and PrEP care logistics such as remembering to take medication and attend appointments. Furthermore, because LTC patients remain at high-risk of HIV acquisition, proactive re-engagement initiatives can be useful. LTC studies such as this can be beneficial to improve retention for PrEP programs, although additional studies are needed to assess reasons for LTC among different PrEP populations. Overall, improving PrEP implementation and retention is critical for ending the HIV epidemic, and our findings have policy implications for public health agencies and funding organizations who support HIV prevention initiatives for urban youth.

CONFLICTS OF INTEREST

The authors declare that they have no competing interests.

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APPENDIXES

Appendix A

Administration of Survey Tool

Potential patients were first identified using the clinic's EMR reporting system where a list of patients who were prescribed TDF/FTC for PrEP, but not seen by a clinician within the last 4 calendar months, was generated. Patient names were extracted into a spreadsheet stored on a HIPAA-secure server, accessible only by delegated study personnel. Delegated study personnel received phone script training from senior research and clinical staff that included "real-world" scenario phone call interviews prior to conducting live phone interviews with PrEP participants in accordance with FDA[1] and NIH[2] guidelines. The first 10 "live" phone calls made by study personnel were supervised by the PI, clinician, research coordinator, or other delegated clinic staff members to ensure adequate delivery of all consent information and consistent approach to survey administration;in addition, a minimum of two telephone calls per day throughout the study period was conducted with the PI or research coordinator present to ensure continued adherence to the consent script.

Calls were made from a dedicated phone line housed within a secure providers' suite at the clinic and the IT Department ensured the telephone line displayed as "Philadelphia, PA" on caller ID. Delegated study personnel were allowed three contact attempts by phone to each LTC patient. If unsuccessful, patients were designated as unreachable. Study personnel left voicemail messages (if able) identifying themselves as working with the patient's assigned care provider (MD/CRNP) and asked for their call to be returned. Study personnel were instructed not to mention PrEP or any other medical terminology relevant to sexual health care to protect patient confidentiality.

Study personnel documented each call attempt and whether a voicemail was left in the secure spreadsheet to ensure patients were not called more than three times. Alternative means of contact, such as email, were used to reach out to patients for the following reasons: to arrange a consent/survey call time and to communicate updated contact information. These contacts were also described in the secure spreadsheet to avoid excessive contact attempts. Only preferred means of contact listed within the EMR system or on patient information documents were used for the purpose of this study, and patient identities were verified by having patients answer 1 of the following questions: Question 1) "Do you remember who you saw or worked with when you came to Y-HEP? (*Acceptable answers included a name or physical description of a CRNP, MD, benefits coordinator, MA, etc.*), Question 2) "Do you remember where Y-HEP is located? (*Acceptable answers could include Locust St, Broad and Locust, Center City near Cosi and Dunkin Donuts, etc.*), or Question 3) "What floor did you go to when you came to Y-HEP? (*Acceptable answers are 2 or 3*).

Once delegated study personnel made contact with a patient identified within the EMR spreadsheet, they read the following:

Hi, Myname is _____ and I work for Y-HEP Health Center. We are currently conducting a survey on why patients become lost-to-care from the "I Am Men's Health" PrEP program, and I was hoping to ask you a few questions about why you haven't been to Y-HEP in a while. If you choose to participate, personal identifying information, such as your name and telephone number,will not be used when reporting results. Your responses will be written down, assigned a survey number, and stored separately from this consent form.

We hope to use the results of this survey to improve the care we provide PrEP program participants. Therefore, I need to ask for your consent to use the information you provide in our conversation. Participation is voluntary. If you don't want to participate in the survey or do not want to answer specific questions you can stop the survey at any time or skip individual questions. Some of the questions in this survey are about personal matters that can be hard to talk about. Thinking or talking about these questions may make you feel anxious, sad, or angry. If you experience any of these feelings, please let me know right away. Remember, you can stop the survey or skip questions at any time. Y-HEP staff are available to help if you are experiencing negative emotions at the end of survey. Finally, your participation in this survey study will have no effect on your ability to restart your participation in PrEP or receive healthcare services at Y-HEP. Just to recap, we called you because we haven't seen you at Y-HEP in 4 months or more, and we wanted to ask you some questions. You don't have to participate, but, if you do, we will keep your information private and you can come back to Y-HEP if you ever want to.

Do you consent to participation in this "I Am Men's Health" PrEP Program Loss of Care survey?

☐ **Yes** ☐ **No** (Interviewer: Note if response is "No", do not proceed. Offer to transfer the patient to a Y-HEP staff member.)

If you have any additional questions concerning this research or your participation in it, please feel free to contact Helen Koenig, MD, PrEP Medical Director, or Caitlin Conyngham, Director of PrEP Programs, at any time. They can be reached by dialing the Philadelphia FIGHT or Y-HEP Health Center main telephone numbers. I can provide you with those numbers if you would like them.

Please answer these questions honestly and to the best of your recollection. Remember, the main goal of this research is to understand how we can make the "I Am Men's Health" PrEP program better.

If the subject declined participation, study personnel used the provided consent face sheet to record the patient's name, the date of the presentation of verbal consent, and document that consent was not given using the appropriate check box. If the patient provided consent to participate, study personnel used the provided consent face sheet to record the patient's name, the date of the presentation of verbal consent, and document that consent was obtained and assign the patient a study number. All information provided in the structured phone conversation was identified via assigned study number only. In both cases, the completed face sheets were stored separately from source documents that contained responses to study questions. All consent documentation was physically stored in a locked filing cabinet that was only accessible to delegated study personnel.

Subjects who declined to answer survey questions were separately coded as decline but counted as a successful contact. Subject's answers were recorded verbatim and multiple answers were permitted.

1. Informed Consent Information Sheet: Guidance for IRBs, Clinical Investigators, and Sponsors. U.S. Department of Health and Human Services; Food and Drug Administration: Web site. http://www.fda.gov. 2014. Accessed June 11, 2019.
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Appendix B

Data Collection Tool

Please answer these questions honestly and to the best of your recollection. Remember, the main goal of this research is to understand how we can make the "I Am Men's Health" PrEP program better.

1. Have any of the following reasons affected your desire or ability to come in regularly for PrEP at Y-HEP? You can say yes to more than one reason, or none of them if none apply to you:

(*Interviewer: Read each response and check each one the subject endorses*)

------- I moved out of the Philadelphia area.
------- I was unable to get transportation to Y-HEP on a regular basis.
------- I do not like coming to Y-HEP for PrEP or other services.
------- I had trouble remembering to come to Y-HEP on a regular basis.
------- Taking my pill every day was difficult.
------- I did not like the side-effects I felt after takingPrEP.
------- I was unable to get time off of work to get to Y-HEP.
------- I thought PrEP was too expensive or I was frustrated by insurance coverage issues.

(*Interviewer: Please ask subject to explain any answers they have chosen and document these notes below*)

Notes:

Are there any other travel, cost, or side effect issues that kept you from coming to Y-HEP for PrEP?

Notes:

2. Now I'd like to ask you a few questions about your experience at the clinic.
Please rate the following items as never (1) sometimes (2) usually (3) or always (4) for the following statements:

(*Interviewer: Read each response and check each one the subject endorses*)

------- How often were non-medical staff courteous and helpful when you visited Y-HEP building?
------- How often did clinicians treat you with courtesy and respect during appointments?
------- How often did clinicians listen to you during appointments?
------- How often were you able to easily schedule appointments?
------- How often did providers explain your PrEP care in a way that was easy to understand?
------- How often were you seen in a reasonable amount of time for a "walk-in" appointment?

(*Interviewer: Please ask subject to explain any answers they have chosen and document these notes below*)

Notes:

Yes/No

Would you recommend the "I am Men's Health" Program to a friend?

(*Interviewer: Circle YES, NO, or neither/other below*)

YES NO NEITHER OTHER

Notes:

Are there any other clinic related issues that kept you from coming to Y-HEP?

Notes:

3. This last set of questions is somewhat personal in nature. Please remember you do not have to answer any or all of the following questions if you do not feel comfortable.

(*Interviewer: Read each response and check each one the subject endorses*)

------- Did you feel pressure to stop PrEP or judgment from family, intimate partner(s), or peers?
------- Do your personal or religious beliefs conflict with taking PrEP?
------- Did you feel taking PrEP caused you to have riskier sex than you did before you started taking PrEP?
------- Have you been diagnosed with a sexually transmitted disease in the last 3 months?
------- Do you have any reason to believe you might have been exposed to HIV in the last 3 months? (*Interviewer: If yes, offer to transfer participant to a Y-HEP clinician*)
------- Are you interested in finding out how you might reenroll in Y-HEP's PrEP Program? (*Interviewer: If the answer is yes, offer to transfer participant to the Y-HEP front desk to be scheduled*)

(Interviewer: Please ask subject to explain any answers they have chosen and document these notes below) Notes:

Those are all the questions I have for you today. Thank you for your participation, and please know that you are welcome to resume care at Y-HEP at any time. Is there anything I can help you with at this time? (*Interviewer: If participants endorse discomfort or upset from the items in section 3, please offer to transfer them to Caitlin Conyngham, PrEP program director, or a Y-HEP clinician*)

Supplementary Table. *PrEP Survey Output*

Record ID	1	2	3	4	5
Complete?	Complete	Complete	Complete	Complete	Complete
Did the patient consent to participate?	Yes	Yes	Yes	No	Yes
Complete?	Complete	Complete	Complete	Complete	Complete
Have any of the following reasons affected your desire or ability to come in regularly for PrEP at Y-HEP? (choice=I moved out of the Philadelphia area.)	Checked	Checked	Unchecked	Unchecked	Unchecked
Have any of the following reasons affected your desire or ability to come in regularly for PrEP at Y-HEP? (choice=I was unable to get transportation to Y-HEP on a regular basis.)	Unchecked	Unchecked	Unchecked	Unchecked	Unchecked
Have any of the following reasons affected your desire or ability to come in regularly for PrEP at Y-HEP? (choice=I do not like coming to Y-HEP for PrEP or other services.)	Unchecked	Unchecked	Unchecked	Unchecked	Unchecked
Have any of the following reasons affected your desire or ability to come in regularly for PrEP at Y-HEP? (choice=I had trouble remembering to come to Y-HEP on a regular basis.)	Unchecked	Unchecked	Checked	Unchecked	Unchecked
Have any of the following reasons affected your desire or ability to come in regularly for PrEP at Y-HEP? (choice=Taking my pill every day was difficult.)	Unchecked	Unchecked	Unchecked	Unchecked	Unchecked
Have any of the following reasons affected your desire or ability to come in regularly for PrEP at Y-HEP? (choice=I did not like the side-effects I felt after taking PrEP.)	Unchecked	Unchecked	Unchecked	Unchecked	Unchecked
Have any of the following reasons affected your desire or ability to come in regularly for PrEP at Y-HEP? (choice=I was unable to get time off of work to get to Y-HEP.)	Unchecked	Unchecked	Checked	Unchecked	Unchecked
Have any of the following reasons affected your desire or ability to come in regularly for PrEP at Y-HEP? (choice=I thought PrEP was too expensive or I was frustrated by insurance coverage issues.)	Unchecked	Checked	Unchecked	Unchecked	Checked
Are there any other travel, cost, or side effect issues that kept you from coming to Y-HEP for PrEP?	Yes, moved to Atlanta	Moved for work/school to Florida; family paying $1,000/mo.	Work schedule, far from you, aged out (26); Insurance was cut off because of income cutoff		Money, no insurance, monogamous relationship, PrEP did not seem worth it
How often were non-medical staff courteous and helpful when you visited Y-HEP building?	Always	Always	Always		
How often did clinicians treat you with courtesy and respect during appointments?	Always	Always	Always		
How often did clinicians listen to you during appointments?	Always	Always	Always		
How often were you able to easily schedule appointments?	Always	Always	Usually		
How often did providers explain your PrEP care in a way that was easy to understand?	Always	Always	Always		
How often were you seen in a reasonable amount of time for a 'walk-in' appointment?	Always	Usually	Usually		
Other		Disorganized, wait would be very long, 1-2 hours for routine testing.	work schedule, they did try to work with you		
Would you recommend the 'I am Men's Health' Program to a friend?	Yes	Yes	Yes		
Notes		No, moved out of the area, insurance charge			
Complete?	Complete	Complete	Complete	Complete	Complete
Did you feel pressure to stop PrEP or judgment from family, intimate partner(s), or peers?	No	No	No		
Do your personal or religious beliefs conflict with taking PrEP?	No	No	No		
Did you feel taking PrEP caused you to have riskier sex than you did before you started taking PrEP?	No	No	No		
Have you been diagnosed with a sexually transmitted disease in the last 3 months?	No	No	No		
Do you have any reason to believe you might have been exposed to HIV in the last 3 months?	No	No	Yes		
Are you interested in finding out how you might re-enroll in Y-HEP's PrEP Program?	No	No	No		

Record ID	6	7	8	9	10
Complete?	Complete	Complete	Complete	Complete	Complete
Did the patient consent to participate?	Yes	Yes	Yes	Yes	Yes
Complete?	Complete	Complete	Complete	Complete	Complete
Have any of the following reasons affected your desire or ability to come in regularly for PrEP at Y-HEP? (choice=I moved out of the Philadelphia area.)	Unchecked	Unchecked	Checked	Unchecked	Checked
Have any of the following reasons affected your desire or ability to come in regularly for PrEP at Y-HEP? (choice=I was unable to get transportation to Y-HEP on a regular basis.)	Unchecked	Unchecked	Unchecked	Unchecked	Unchecked
Have any of the following reasons affected your desire or ability to come in regularly for PrEP at Y-HEP? (choice=I do not like coming to Y-HEP for PrEP or other services.)	Unchecked	Unchecked	Unchecked	Unchecked	Unchecked
Have any of the following reasons affected your desire or ability to come in regularly for PrEP at Y-HEP? (choice=I had trouble remembering to come to Y-HEP on a regular basis.)	Unchecked	Unchecked	Unchecked	Unchecked	Unchecked
Have any of the following reasons affected your desire or ability to come in regularly for PrEP at Y-HEP? (choice=Taking my pill every day was difficult.)	Unchecked	Unchecked	Unchecked	Unchecked	Unchecked
Have any of the following reasons affected your desire or ability to come in regularly for PrEP at Y-HEP? (choice=I did not like the side-effects I felt after taking PrEP.)	Unchecked	Unchecked	Unchecked	Unchecked	Unchecked
Have any of the following reasons affected your desire or ability to come in regularly for PrEP at Y-HEP? (choice=I was unable to get time off of work to get to Y-HEP.)	Checked	Unchecked	Unchecked	Unchecked	Unchecked
Have any of the following reasons affected your desire or ability to come in regularly for PrEP at Y-HEP? (choice=I thought PrEP was too expensive or I was frustrated by insurance coverage issues.)	Unchecked	Unchecked	Unchecked	Unchecked	Unchecked
Are there any other travel, cost, or side effect issues that kept you from coming to Y-HEP for PrEP?		Never used PrEP. Only used PEP. No longer wants to be associated with Y-HEP	Aged out, intimate relationships, Moved out of Philly		Moved out of Philly area, to another state
How often were non-medical staff courteous and helpful when you visited Y-HEP building?	Always		Always	Always	
How often did clinicians treat you with courtesy and respect during appointments?	Always		Always	Always	
How often did clinicians listen to you during appointments?	Always		Always	Always	
How often were you able to easily schedule appointments?	Sometimes		Usually		
How often did providers explain your PrEP care in a way that was easy to understand?	Always		Always	Always	
How often were you seen in a reasonable amount of time for a 'walk-in' appointment?	Usually		Usually	Always	
Other	When you leave a note, there's a long line, people forget			Note for "easily schedule appointments" question: walk-in	Everything was excellent, just moved
Would you recommend the 'I am Men's Health' Program to a friend?	Yes		Yes	Yes	Yes
Notes					
Complete?	Complete	Complete	Complete	Complete	Complete
Did you feel pressure to stop PrEP or judgment from family, intimate partner(s), or peers?	No		No	No	No
Do your personal or religious beliefs conflict with taking PrEP?	No		No	No	No
Did you feel taking PrEP caused you to have riskier sex than you did before you started taking PrEP?	No		No	No	No
Have you been diagnosed with a sexually transmitted disease in the last 3 months?	No		No	No	No
Do you have any reason to believe you might have been exposed to HIV in the last 3 months?	No		No	No	No
Are you interested in finding out how you might re-enroll in Y-HEP's PrEP Program?	Yes		No	No	No

Key: Checked: Yes/Affirmative Response; Unchecked: No/Negative Response

Record ID	11	12	13	14
Complete?	Complete	Complete	Complete	Complete
Did the patient consent to participate?	Yes	Yes	Yes	Yes
Complete?	Complete	Complete	Complete	Complete
Have any of the following reasons affected your desire or ability to come in regularly for PrEP at Y-HEP? (choice=I moved out of the Philadelphia area.)	Checked	Checked	Unchecked	Checked
Have any of the following reasons affected your desire or ability to come in regularly for PrEP at Y-HEP? (choice=I was unable to get transportation to Y-HEP on a regular basis.)	Unchecked	Unchecked	Unchecked	Checked
Have any of the following reasons affected your desire or ability to come in regularly for PrEP at Y-HEP? (choice=I do not like coming to Y-HEP for PrEP or other services.)	Unchecked	Unchecked	Unchecked	Checked
Have any of the following reasons affected your desire or ability to come in regularly for PrEP at Y-HEP? (choice=I had trouble remembering to come to Y-HEP on a regular basis.)	Unchecked	Unchecked	Checked	Unchecked
Have any of the following reasons affected your desire or ability to come in regularly for PrEP at Y-HEP? (choice=Taking my pill every day was difficult.)	Unchecked	Unchecked	Checked	Unchecked
Have any of the following reasons affected your desire or ability to come in regularly for PrEP at Y-HEP? (choice=I did not like the side-effects I felt after taking PrEP.)	Unchecked	Unchecked	Unchecked	Unchecked
Have any of the following reasons affected your desire or ability to come in regularly for PrEP at Y-HEP? (choice=I was unable to get time off of work to get to Y-HEP.)	Unchecked	Unchecked	Checked	Unchecked
Have any of the following reasons affected your desire or ability to come in regularly for PrEP at Y-HEP? (choice=I thought PrEP was too expensive or I was frustrated by insurance coverage issues.)	Unchecked	Checked	Unchecked	Unchecked
Are there any other travel, cost, or side effect issues that kept you from coming to Y-HEP for PrEP?	No	Yes, but moved back to Philly for college (essentially in and out of Philly for college). Got a letter from LabCorp asking for insurance info but w/out reply cost would be $700, but confused because thought testing should be covered, confusion about whether costs were covered by center	-took pill erratically, out of sight, out of mind-just started working more jobs, 3 at once-email reminders would be helpful for appointments	-never lived in Philly area-is activities coordinator at another LGBT organization-said didn't receive healthcare from PrEP
How often were non-medical staff courteous and helpful when you visited Y-HEP building?	Always	Always	Always	
How often did clinicians treat you with courtesy and respect during appointments?	Always	Always	Always	
How often did clinicians listen to you during appointments?	Always	Usually	Always	
How often were you able to easily schedule appointments?	Always	Always	Always	
How often did providers explain your PrEP care in a way that was easy to understand?	Always	Always	Sometimes	
How often were you seen in a reasonable amount of time for a 'walk-in' appointment?	Always	Always		
Other			At the time, he understood PrEP instructions but it was hard to take every day.	
Would you recommend the 'I am Men's Health' Program to a friend?	Yes	Yes	Yes	
Notes		No	No	
Complete?	Complete	Complete	Complete	Complete
Did you feel pressure to stop PrEP or judgment from family, intimate partner(s), or peers?	No	No	No	
Do your personal or religious beliefs conflict with taking PrEP?	No	No	No	
Did you feel taking PrEP caused you to have riskier sex than you did before you started taking PrEP?	No	No	Yes	
Have you been diagnosed with a sexually transmitted disease in the last 3 months?	Yes	No	No	
Do you have any reason to believe you might have been exposed to HIV in the last 3 months?	No	No	Yes	
Are you interested in finding out how you might re-enroll in Y-HEP's PrEP Program?	No	No	Yes	

Record ID	15	16	17	18	19
Complete?	Complete	Complete	Complete	Complete	Complete
Did the patient consent to participate?	Yes	Yes	Yes	Yes	Yes
Complete?	Complete	Complete	Complete	Complete	Complete
Have any of the following reasons affected your desire or ability to come in regularly for PrEP at Y-HEP? (choice=I moved out of the Philadelphia area.)	Unchecked	Unchecked	Checked	Checked	Unchecked
Have any of the following reasons affected your desire or ability to come in regularly for PrEP at Y-HEP? (choice=I was unable to get transportation to Y-HEP on a regular basis.)	Checked	Unchecked	Unchecked	Unchecked	Unchecked
Have any of the following reasons affected your desire or ability to come in regularly for PrEP at Y-HEP? (choice=I do not like coming to Y-HEP for PrEP or other services.)	Unchecked	Unchecked	Unchecked	Checked	Unchecked
Have any of the following reasons affected your desire or ability to come in regularly for PrEP at Y-HEP? (choice=I had trouble remembering to come to Y-HEP on a regular basis.)	Unchecked	Unchecked	Unchecked	Unchecked	Checked
Have any of the following reasons affected your desire or ability to come in regularly for PrEP at Y-HEP? (choice=Taking my pill every day was difficult.)	Unchecked	Unchecked	Unchecked	Unchecked	Unchecked
Have any of the following reasons affected your desire or ability to come in regularly for PrEP at Y-HEP? (choice=I did not like the side-effects I felt after taking PrEP.)	Checked	Unchecked	Unchecked	Unchecked	Unchecked
Have any of the following reasons affected your desire or ability to come in regularly for PrEP at Y-HEP? (choice=I was unable to get time off of work to get to Y-HEP.)	Checked	Unchecked	Checked	Unchecked	Unchecked
Have any of the following reasons affected your desire or ability to come in regularly for PrEP at Y-HEP? (choice=I thought PrEP was too expensive or I was frustrated by insurance coverage issues.)	Checked	Checked	Unchecked	Unchecked	Unchecked
Are there any other travel, cost, or side effect issues that kept you from coming to Y-HEP for PrEP?	lack of car fare	Initially on PrEP in 2014 through Y-HEP, insurance covered some and Y-HEP covered the remainder. Went off PrEP due to break-up and not sexually active, when re-starting new insurance could not cover costs.	#NAME?	Lives in Georgia now; felt like he became aroused all the time when he started taking PrEP	No
How often were non-medical staff courteous and helpful when you visited Y-HEP building?	Always	Usually	Always	Always	Always
How often did clinicians treat you with courtesy and respect during appointments?	Always	Usually	Always	Always	Always
How often did clinicians listen to you during appointments?	Always	Usually	Always	Always	Always
How often were you able to easily schedule appointments?	Never	Never	Always	Always	Always
How often did providers explain your PrEP care in a way that was easy to understand?	Always	Always	Usually	Always	Always
How often were you seen in a reasonable amount of time for a 'walk-in' appointment?	Always	Usually	Usually	Always	Always
Other	No		If there was more info to take home and read on his own would've been helpful.		
Would you recommend the 'I am Men's Health' Program to a friend?	Yes	Yes	Yes	Other	Yes
Notes		No, found different primary care and on PrEP again, also using an assistance program	Weekend appointments if possible would be helpful		
Complete?	Complete	Complete	Complete	Complete	Complete
Did you feel pressure to stop PrEP or judgment from family, intimate partner(s), or peers?	No	No	No	No	No
Do your personal or religious beliefs conflict with taking PrEP?	No	No	No	No	No
Did you feel taking PrEP caused you to have riskier sex than you did before you started taking PrEP?	No	Yes	Yes	No	Yes
Have you been diagnosed with a sexually transmitted disease in the last 3 months?	No	No	No	No	No
Do you have any reason to believe you might have been exposed to HIV in the last 3 months?	No	Yes	No	No	No
Are you interested in finding out how you might re-enroll in Y-HEP's PrEP Program?	Yes	No	Yes	No	Yes