

# Wellness Guide

WHAT YOU NEED TO KNOW ABOUT  
**PREVENTING HIV WITH PrEP**



# Welcome!



This guide has basic information for individuals receiving substance use disorder treatment about preventing HIV with **pre-exposure prophylaxis (PrEP)**. Continue reading to learn how this information can contribute to your overall wellness planning!

## IN THIS GUIDE:

- Resources for HIV prevention & testing
- What to expect from PrEP

*A glossary of terms is included on page 33-34!*

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**Section 1:**

# **PrEP Overview**

# About PrEP

Pre-Exposure Prophylaxis (PrEP) is medicine taken on an ongoing basis to prevent HIV, a virus that infects immune cells and stops them from protecting the body from illness. When a person is exposed to HIV through sex or injection drug use, PrEP can prevent HIV transmission.

**Some compare PrEP to taking birth control pills. The main purpose of taking the medicine is to prevent what would likely occur without any pills to stop it.**

People who take PrEP as prescribed can reduce their risk of acquiring HIV by up to:

- **99%** when related to sexual transmission
- **74 %** when related to injection drug use

**Because of its effectiveness in preventing HIV, it is important to learn more about PrEP to consider if it could assist with your overall wellness planning.**



# How Does PrEP Work?

If HIV enters the body of someone who uses PrEP as prescribed, the medicine keeps HIV from being able to cause an infection; therefore, keeping the person HIV negative.

PrEP works by blocking HIV before it is able to lead to an HIV infection.



For PrEP to work best, it is necessary to take it exactly as prescribed, which could be taking a daily pill or getting an injection as few as 6 times per year.



# PrEP vs. ART

PrEP and ART (Antiretroviral Therapy) are similar medications that do very different things. **PrEP is used to prevent HIV**, while **ART is used to treat HIV**. PrEP consists of some of the same medicines as ART but is not used in the same dose or combination. There are some key differences between the two, such as:

PrEP	ART
<ul style="list-style-type: none"><li>• Designed to <b>PREVENT</b> HIV in people who are vulnerable to HIV</li><li>• Consists of <b>two</b> anti-HIV medications from two different classes of drugs, or one drug from one class</li><li>• <b>Not used</b> for treating HIV</li></ul>	<ul style="list-style-type: none"><li>• Designed to <b>TREAT</b> HIV in people living with HIV</li><li>• Usually consists of <b>three</b> anti-HIV medications from at least two different classes of drugs</li><li>• <b>Effective</b> for treating HIV</li></ul>

PrEP is not powerful enough to stop HIV in people who are HIV positive and can limit the effectiveness of ART once an antiretroviral regimen is started, so it's important to know the differences between the two!



For more information on ART and HIV treatment, see our **Wellness Guide: What you need to know about HIV Prevention and Care**



# **Section 2:**

# **Preventing HIV**



# PrEP and Substance Use

There are about 1.2 million people living with HIV in the US, including around 154,700 people who don't know their status.

Because people who use substances have increased vulnerability to HIV, it is recommended that they are educated about PrEP and consider if it would be helpful to support their wellness.

## Why do people with substance use disorder have increased vulnerability to acquiring HIV?

Using injection drugs can lead to HIV transmission if you share needles, syringes, or other drug preparation equipment. About 1 in 10 new HIV infections are attributed to injection drug use.

**Drinking alcohol and ingesting, smoking, or inhaling drugs are also associated with increased risk for HIV**

**Alcohol and other drug use can impair judgment**

**This can lead to practices, like condomless sex or sharing syringes, that make people more likely to get and transmit HIV**



# HIV Prevention for Injection Drug Use

It is best to use sterile needles or syringes AND works every time!

Using sterile needles or syringes and injection equipment can greatly reduce your likelihood of acquiring HIV. Getting new syringes ensures that they are sterile.

## WHERE TO GET STERILE SYRINGES OR NEEDLES

- Local syringe service programs (SSPs)
  - SSPs provide sterile syringes and injection equipment.
  - Find an SSP here: <https://nasen.org/>
- Pharmacies (*some sell new needles or syringes*)
- Medical providers (*some can write prescriptions for new needles or syringes*)

## STERILIZATION TIPS

If getting new needles or syringes isn't an option for you, then there are ways you can sterilize the syringes that you do have.

If new, sterile needles or syringes aren't available, cleaning should follow 3 steps with each taking 30 seconds:

1. Rinse needle or syringe out with clean water.  
(*repeat until water is clear*)
2. Disinfect needle or syringe with pure bleach.
3. Rinse needle or syringe out again with clean water.

Even needles or syringes that haven't been used for a while should be sterilized – viruses can still be infectious!

<https://harmreduction.org/resource-center/harm-reduction-near-you/>

The National Harm Reduction Coalition has links that can help you find harm reduction resources and tools that you need to keep yourself and your community safe & healthy.

# Reducing Sexual Transmission of HIV

PrEP is recommended as one tool among many to reduce risk of HIV. Condom use is recommended while taking PrEP to prevent sexually transmitted infections (STIs).

When used the right way every time, condoms – both internal (female) and external (male) – are **highly effective in preventing HIV and many STI**



## *Tips for proper condom use:*



- Use a new condom for every time you have penetrative sex.
  - Don't double up! This can increase likelihood of condom breakage.
  - Make sure you use enough lubrication to avoid tearing the skin and reduce risk of HIV transmission
- *Avoid oil-based lubricants, like baby oil, lotion, Vaseline, or cooking oil as they will cause latex condoms to break*

**Sexual wellness and harm reduction are important for everyone!**



# PrEP, Women, and Pregnancy

- PrEP is not used enough. In one study, only about 30% of people who could be helped by PrEP were taking it. Moreover, women comprise only about 10% of people taking PrEP.
- Most women acquire HIV through heterosexual contact and injection drug use.
- Pregnant people can take PrEP during and after pregnancy. However, complications may occur and people wanting to become pregnant should consult with their medical provider.

## Prevent Transmission During Pregnancy



HIV can be transmitted to the baby during pregnancy, childbirth and breastfeeding. This is referred to as “perinatal transmission.”

**All pregnant people should be tested twice during every pregnancy;** as early as possible and again in the third trimester.



If a pregnant person is HIV positive, it is important to take HIV medications as prescribed to greatly reduce risk of transmitting HIV to the baby.

## **Section 3:**

# **Before Starting PrEP**

# Considering PrEP

## People who might benefit from taking PrEP include:

- Men who have sex with men
- People who have multiple sex partners
- People who have a sex partner who is living with HIV
- People with a sex partner with unknown HIV status
- People who use injection drugs
- People who have recently had a sexually transmitted infection (STI)



**Is PrEP right  
for me?**



If you think PrEP may be right for you, make an appointment with a medical provider to learn more about your options.

***PrEP is not right for people who are living with HIV as there are other medicines to keep them healthy.***

# PrEP Medicines

## How is PrEP taken?

- PrEP is typically prescribed as a daily pill. For those who have difficulty taking pills on a daily basis, it can also be injected every two months.
- Individuals need to consult with their medical provider to decide if the daily pill or an injection every two months would be best.

## Are there any side effects?

When starting PrEP, some symptoms may include:

- Diarrhea
- Nausea
- Abdominal pain
- Headaches
- Fatigue
- Injection site reaction (if taking injectable)

Fortunately, the side effects of PrEP are often few and generally short-lived!



***If you experience ongoing discomfort, consult with a medical provider!***

# Preparing for Your First PrEP Visit

## Medical History

PrEP providers will want some information about your medical history, such as:

- Current medicines taken
- Other medical conditions
- Allergies
- Insurance information (*many providers can assist with obtaining coverage*)

## Appointment Preparation

### Transportation

If you can't drive, get a ride or take public transportation to your appointment, talk to your counselor if they know about resources.

### Is there someone you can take with you?

Many find that having a support person with them can reduce anxiety.

### Consider writing notes

It's hard to keep track of a lot of new information – especially when it's complicated medical info!

### There are no bad questions!

Medical and health information can sometimes be difficult to understand. Don't be afraid to ask the medical provider to repeat or explain something.

### Patient portals

Many medical providers have patient portals, which are websites that allow patients to see their personal health information, such as lab results.



# What to Expect During Your First PrEP Appointment

**During your first PrEP appointment you can expect that your provider will:**

- Conduct an HIV test to ensure that you do not have HIV
- Test your kidney function to make sure that PrEP is a safe medication for you
- Conduct tests for Sexually Transmitted Infections (STIs) and offer treatment, as needed
- Conduct test for hepatitis B virus

**If test results indicate that PrEP might be right for you, the provider will then:**

- Discuss different PrEP medications (pill or injection)
- Discuss possible side effects of PrEP
- Review the need for ongoing HIV testing
- Review the schedule of subsequent visits
- Emphasize the importance of medication adherence
- Discuss risks associated with pregnancy or acquiring STIs
- Discuss HIV risk reduction



***These topics will be covered in the rest of this Wellness Guide***

# The Role of HIV Testing in PrEP Care

Since people taking PrEP have ongoing likelihood of exposure to HIV, HIV screening is needed:

- Before starting PrEP
- Every three months when taking the daily pill.
- Every two months when taking PrEP injections



Confirming that you remain HIV negative while taking PrEP is essential because PrEP can be harmful to people who have HIV and can make it more difficult to effectively treat HIV over time.

People on PrEP should let their medical provider know if they experience any of the following symptoms associated with **acute HIV infection**:

- Fever
- Flu-like symptoms
- Fatigue

*HIV medications may be prescribed until testing can confirm that you do not have HIV.*

If diagnosed with HIV while taking PrEP, you will need to shift to taking ART medications right away to ensure you are receiving the care needed to fully treat HIV.

For more information on ART and HIV treatment, see our **Wellness Guide: What you need to know about HIV Prevention and Care**



# Types of HIV Tests

There are different types of HIV tests – lab-based tests are the most accurate and needed for monitoring HIV status when taking PrEP, rapid tests are the most convenient but are much less sensitive than other types of tests.

## Lab-Based Tests

- Require a blood draw that is sent to a lab for analysis
- Most accurate and have the shortest window period (10-45 days)
- Can also detect the actual virus in the blood
- Needed to confirm rapid test results



## Rapid Tests



- Use a fingerstick or oral fluid
- Results within 20 minutes
- Window period is up to 90 days
- Can be done at home or in a clinical setting

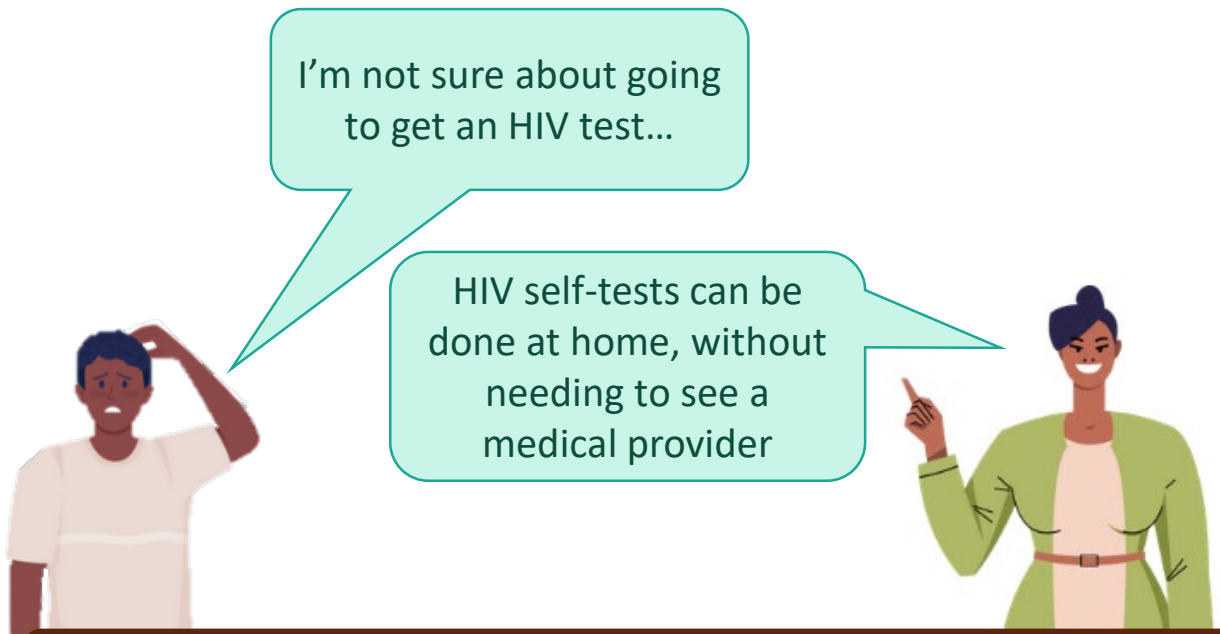
### ***What's a Window Period?***

The time period between actual moment of HIV infection and a test's ability to detect HIV infection. A test with a shorter window period is preferred when ruling out HIV infection.



# Self-Testing

Some people may experience barriers to being tested by a medical provider. Self-tests are a good alternative, and you can get them online or at a pharmacy. However, positive results will need to be confirmed with lab-based tests.



## Types of Self-Tests

**Rapid Self-Tests** use oral fluid and results are available in 20 minutes, while they are accurate in detecting HIV, they have the longest window period (90 days). In other words, if someone acquired HIV *less* than 90 days ago, this test may not detect it. Order a rapid test at:

<https://www.phillykeeponloving.com/> for Philadelphia county or

<https://www.getmyhivtest.com/> for the rest of PA



**Mail-In Self-Tests** include supplies to collect dried blood from a fingerstick at home. The sample is then sent to a lab for testing and the results are provided by a health care provider.

➔ Order a mail-in test at <https://www.testing.com/tests/at-home-HIV-test/>

# Finding a PrEP Provider

If you need to locate a provider to get PrEP:

- Visit Pennsylvania Department of Health at [health.pa.gov](http://health.pa.gov)
- Call a local community health clinic
- Visit <http://prelocator.org>

There are many places in PA that offer PrEP. Visit the link below or scan the QR code to find a provider near you.



[bit.ly/DOHmap](http://bit.ly/DOHmap)



Below is a brief overview of how to use the online map of PrEP resources.

**Overview**

**Information Button**

**Search Bar**

**Directions Button**

**Near Me Button**

**Facility Information**

**Information Button**

**Layers Feature**

The screenshot shows a web browser displaying the "Pennsylvania HIV and Viral Hepatitis Service Providers" map. The map is populated with numerous colored pins representing providers. A search bar at the top allows users to find providers by county, zip code, or city. A "Near Me" button is located in the upper right corner of the map area. A "Directions" button is also present. A "Facility Information" window is open, showing details for "A BETTER TODAY, INC." in Sullivan County. A "Layers" feature is visible on the left side of the map, allowing users to filter providers by category such as "Hepatitis A", "Hepatitis B", "Hepatitis C", "HIV Testing Services", "State Health Centers", and "Drug and Alcohol Treatment". An "Information" button is also highlighted on the map.

The map can be viewed on a computer or mobile device. If you don't have access to either, don't hesitate to ask your medical provider for help!



# Insurance Access

Most insurance plans and State Medicaid programs cover PrEP. If you need help accessing care, check out the resources below.

## Ready, Set, PrEP

Ready, Set, PrEP makes PrEP medications available at no cost to those who qualify: <https://readyssetprep.hiv.gov/>

## *Other resources to help:*

- Co-pay assistance programs help lower the costs of PrEP medications. Income is not a factor in eligibility.
- Assistance is also available at: [www.gileadadvancingaccess.com](http://www.gileadadvancingaccess.com) or [www.hiv.gov/federal-response/ending-the-hiv-epidemic/prep-program](http://www.hiv.gov/federal-response/ending-the-hiv-epidemic/prep-program).

## Marketplace

Open Enrollment Nov. 1 through Dec. 15, unless qualify for Special Enrollment Period (SEP). More details online. [www.healthcare.gov](http://www.healthcare.gov) 800-318-2596

## Navigator Programs

<https://www.pa211.org/get-help/health/navigator-programs/>

## PA Health & Dental Marketplace

Link to additional financial assistance from the American Rescue Plan to lower your monthly payment and/or out-of-pocket expenses. <https://pennie.com/>

## State and local Health Insurance Info & Counseling

Can search by county, zip & city. Population specific resources (aging, vets, etc) included. <https://www.pa211.org/get-help/health/state-local-health-insurance-information-counseling/>

## **Section 4:**

# **Managing PrEP**

# What to Expect While Taking PrEP

You will need to see your medical provider every 3 months for oral medicines and every 2 months for injectable medicines.

Your provider will:

- Test for HIV, STIs, kidney function, and pregnancy (if appropriate) at follow-up visits
- Ask about any medication side effects or symptoms related to a possible acute HIV infection (e.g., fever)
- Discuss HIV risk reduction and provide condoms

***If I am taking PrEP, do I still need to use condoms?***



Although PrEP can prevent HIV, it is **important to also engage in other HIV prevention practices** such as **using condoms** and using **sterile injection equipment**.

- Sterilizing drug equipment also helps to reduce exposure to HIV and other viral infections, like Hepatitis C.
- Condom use is important to prevent sexually transmitted infections, which can increase vulnerability to acquiring HIV.



# Medication Adherence

**For PrEP to work, it is important to take it as prescribed.**

- ✓ Adherence means **to stick to something**.
- ✓ For maximum protection, there needs to be **enough medication** in the body for a **long enough time** to do its job, which is to **PREVENT HIV INFECTION**.
- ✓ When someone is non-adherent to their PrEP regimen (they don't take it the way their medical provider instructed), they are more vulnerable to acquiring HIV.

**PrEP needs to be taken consistently in advance of HIV exposure to work best. PrEP is not as effective if it is not taken as prescribed.**

Taking your medication exactly as prescribed keeps you healthy and helps make sure your medication keeps working.

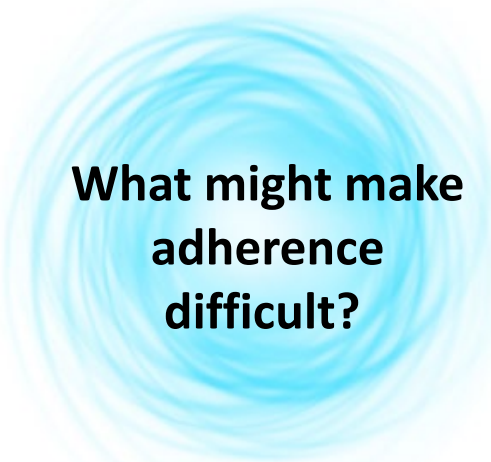
**See next 2 pages for tips for remaining adherent!**

# Problem Solving

## Setting yourself up for success!

It can be helpful to do some problem solving *before* issues with adherence come up. Some questions to ask yourself:

- What are my concerns about adherence?
- What might make adherence hard for me?
- Who can I talk to about my concerns?
- Where can I get more information?
- Who can help me find solutions to challenges I face?



## What might make adherence difficult?

- Work, childcare, being busy
- Being tired of taking meds
- Side effects
- Unstable housing
- Mental health challenges
- Arrest or incarceration

Financial problems, such as paying for PrEP care and/or basic needs, can also interfere with adherence. If you're having difficulties, consult your counselor or case manager for assistance. You can also find information about financial resources on the Insurance Access page (page 22).

# Adherence Tools

## Tools for remembering to take your oral PrEP

- ❑ Alarm clock
- ❑ Alerts, reminders or alarms in your phone
- ❑ Take meds at the same time as something you do every day – *when you brush your teeth, get ready for bed, make coffee*
- ❑ Have a friend help remind you
- ❑ Keep a pill card in your pocket to keep track of each pill taken
- ❑ Put a calendar up and mark each day you take your meds
- ❑ Pill boxes
  - ❑ *Tip! Some pillboxes can be attached to a lanyard so you can keep your meds close to you if you're nervous about theft or sharing your private health information.*

**What tools can YOU think of that might help you keep on track with taking your medication?**

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If you miss a dose - don't beat yourself up! We all forget to do things sometimes.

Don't double up – take the next dose as usual, unless otherwise directed by your doctor.

If you have missed several doses in a row, it's a good idea to check in with your medical provider.

# Do I Need to Take PrEP Forever?

## You may decide to stop taking PrEP if:

- You are not sexually active or using injection drugs
- You are in a monogamous (1 partner) relationship with a person who is HIV-negative
- You are not able to be adherent to taking medicine
- You are experiencing ongoing side effects

Before stopping PrEP, it is important to consult with a medical provider to make sure you follow the necessary steps to maintain your wellness.

**For most people, PrEP can be started and stopped as their need for protection changes.**



If you decide to resume taking PrEP, it is important to meet with your medical provider to confirm that you remain HIV uninfected and for other tests.

# Telehealth Visits

Some people may experience barriers to receiving PrEP, particularly if they live in rural and underserved areas. When transportation is a problem, telehealth visits via telephone or computer can be a great alternative.



HIV and other medical testing can be performed at testing sites closer to home, or by using home testing kits that a person would mail to a laboratory every three months. If a person tests HIV negative, they would continue taking PrEP using a mailed 90-day supply rather than a 30-day prescription with two refills.

If a person on PrEP tests positive for HIV, it is crucial that they get confirmatory testing at a lab and talk to their medical provider. **PrEP does not treat HIV**, so that person would be prescribed anti-retroviral therapy (ART) for HIV.



*Telehealth would **NOT** be an option for those on **injectable PrEP** because they need to receive another injection every second month.*

# **Section 5:**

# **Post-Exposure Prophylaxis**

# PEP: What to know

**PrEP, *Pre-Exposure Prophylaxis*, is medication that can prevent HIV transmission prior to exposure.**

**In contrast, PEP, *Post-Exposure Prophylaxis*, is medication that can prevent HIV transmission after an exposure.**

PEP is the use of antiretroviral drugs after a single high-risk event, such as accidental needle sticks, sexual assault, condomless sex, or a broken condom. **(If you are a victim of sexual assault in PA, call [1-888-772-7227](tel:1-888-772-7227) to find a rape crisis center.)**

**PEP is for emergency situations** and must be started as soon as possible to stop HIV from causing an infection. PEP can be one, two, or (rarely) three pills. To prevent HIV, PEP must be taken for one month.



**PEP must be started within 72 hours of exposure; the sooner the better. If you have been exposed to HIV in the past 72 hours, ask about PEP right away. You can go to an Emergency Room, an Urgent Care provider, or your regular medical provider.**

**PEP is not a substitute for PrEP** and is not recommended for people who may be exposed to HIV frequently. PrEP is a far more effective option for people who are HIV-negative and who may continue to be exposed to HIV.

**Section 7:**

**Appendix**



# Glossary

**Adherence:** Adherence means to stick to something, such as a medication regimen or other instructions to support one's health. When someone is non-adherent to their medication regimen, they may not receive the benefit that the medication can provide.

**Antiretroviral treatment (ART):** HIV medication that stops HIV from replicating and allows the immune system to recover by lowering viral load.

**HIV:** Human Immunodeficiency virus

**HIV Exposure:** An incident like sharing injection equipment or having condomless sex with someone living with HIV.

**Immunodeficiency:** Immunodeficiency refers to a compromised immune system.

**Lab-Based HIV Tests:** Require a blood draw that is sent to a lab for analysis. These tests have the shortest window period (10-45 days) and can detect the actual virus in the blood.

**Mail-In HIV Self-Tests:** Include supplies to collect dried blood from a fingerstick at home. The sample is then sent to a lab for testing and the results are provided by a health care provider.

**PEP: Post-Exposure Prophylaxis:** Antiretroviral medications taken as soon as possible after a potential HIV exposure for someone who is HIV negative to keep them from becoming HIV positive.

# Glossary

**PrEP: Pre-exposure Prophylaxis:** Antiretroviral medications taken on an ongoing basis to protect people from HIV infection who are HIV negative and at ongoing risk of HIV acquisition.

**Rapid HIV Tests:** Tests which use a fingerstick or oral fluid, provide a result within 20 minutes, and can be done entirely at home or in a clinical setting.

**STIs (Sexually Transmitted Infections; also referred to as STDs (Sexually Transmitted Diseases)):** A disease caused by infection with certain bacteria, viruses, or other microorganisms that can be passed from one person to another through blood, semen, vaginal fluids, or other body fluids, during oral, anal, or genital sex with a partner who has HIV.

**Virus:** A virus is an infectious agent that can only replicate inside the cells of a living organism.

**Window Period:** The time period between exposure to HIV and a test's ability to detect an HIV infection.

# Preparing for a Medical Visit

## Patient Worksheet

**NAME:** \_\_\_\_\_

**DATE OF BIRTH:** \_\_\_\_\_

**Current medications:**

- 1.
- 2.
- 3.
- 4.
- 5.

**Other medical conditions or diagnoses**

*(diabetes, asthma, HCV, etc.)*

**Allergies:**

**Family history of medical conditions or diagnoses:**

**Have you taken PrEP before?**    Y        N

If yes, when:

What medicine:

**Checklist of items & information to bring to your first medical appointment:**

- Documents such as lab work, medical records
- Insurance information
- Contact information for other medical providers
- List of questions

# Questions for my Medical Provider

## Patient Worksheet: Medicine

### Medicine

- What are my options?
  
- Side effects
  - What are common side effects?
  
  - What can I do to manage side effects? (*Over the counter medicine, eating before taking meds, etc.*)
  
- Are there any drug/drug interactions I should know about?
  
- What happens if I miss a dose?
  
- How often will I need to see the medical provider or get blood work done?
  
- Is there a particular pharmacy that I need to use?
  
- What kind of follow up or ongoing medical care will I need?
  
- What should I do if my circumstances change and I no longer need PrEP?

# Oral Medicines

Patient Worksheet (page 1 of 2)

## Oral Medication Information & Schedule

**Medication Name:** \_\_\_\_\_

**Directions:** *(how many pills per day, take with food, etc.)*

Questions, Concerns, Notes:

# Oral Medicines

Patient Worksheet (page 2 of 2)

## DAILY MEDICATION TRACKER

Date	Took Meds (y/n)	Notes ( <i>side effects, questions</i> )

# Injectable Medicines

## Patient Worksheet

### Injection Schedule

How often do I need a new injection: \_\_\_\_\_

Dates for upcoming injection appointments: \_\_\_\_\_

Directions for scheduling new appointments: \_\_\_\_\_

### Questions, Concerns, Notes: