



A Toolkit for Advancing the Uptake and Use of PrEP in Indian Country



*Tribal HIV
Initiative*

AT NIHB







Contents

- 1. Introduction4**
 - Background 4
 - Purpose..... 4
 - Language and Terminology..... 5
 - Glossary and Acronyms 7
- 2. What is PrEP? 10**
- 3. Tribal Communities and PrEP 12**
 - Integrating PrEP Services into Existing Tribal and Tribal Organizations’ Services .. 12
 - How IHS supports Tribes and Tribal Organizations Adopting PrEP Services 16
- 4. Who May Use PrEP? 18**
 - Who Should Prescribe PrEP? 18
 - Identifying Candidates for PrEP Initiation 19
 - Obtaining PrEP 21
 - Recommending PrEP..... 22
 - Who may not be a good candidate for PrEP 22
 - Guide for Tribes and Tribal Organizations on the Integration of PrEP Services 25
 - Guide for Community Members 27
- 5. Additional Actions that Tribes or Tribal Organizations Can Take to Integrate PrEP 30**
 - Steps to starting a PrEP program in a community 30
 - How to Raise Awareness in the Community and Reduce Stigma..... 32
 - Aligning PrEP Efforts with Traditional Medicine/Healing..... 33
- 6. Additional Considerations 34**
- 7. Additional Resources 36**



Acknowledgements

This toolkit was made possible by a number of different resources and valuable collaborators.

The content for this toolkit was developed, under the direction of Robert Foley with the National Indian Health Board and Rick Haverkate (Sault Ste. Marie Tribe of Chippewa Indians) with the Indian Health Service, through a subcontract with a team from JSI Research & Training Institute.

- Hannabah Blue (Diné)
- Yvonne Hamby
- Arman Lorz
- Hannah Chidekel

We would like to acknowledge the American Indian and Alaska Native interviewees and advisers involved in the process of developing this toolkit, whose input and feedback helped ensure that this resource is relevant and useful for Tribal communities.

Content advisors:

- Theresa “Terri” Bramel
- Whitney Essex
- Dr. Jorge Mera
- Sheldon Raymore (Cheyenne River Sioux Tribe)

Community interviewees:

- Kurt Begaye (Diné)
- David Clark (Goldbelt shareholder/Alutiiq)
- Lane Holcomb (Cherokee)
- Dr. Jonathan Iralu
- Dr. Madalene Mandap



This toolkit contains links to other sites, tools and resources, as well as graphics, handouts figures, and flowcharts. These have been developed by other dedicated organizations or government entities working in this field. NIHB would like to acknowledge them, and thank them for creating such valuable resources. Rather than recreate some of these tools, NIHB, IHS, and JSI Research & Training Institute have chosen to reproduce them here and provide the link to their original web-based location.

The toolkit was organized by the National Indian Health Board and funded through a cooperative agreement with the Indian Health Service (National Indian Health Outreach and Education II: HIV/AIDS, U252IHS0013-03-03) with resources from the Minority HIV/AIDS Fund.



1. Introduction

BACKGROUND

Roughly one third of American Indian and Alaska Native (herein referred to as “AI/AN” or “Native”) people with HIV do not know that they have this infection.¹ Without knowledge of their status, these individuals do not seek the medical care needed and available to support them. However, Native people also have one of the lowest life expectancies after a diagnosis,² which potentially points to the challenges related to HIV stigma, accessibility to consistent care, relevance of resources, and socioeconomic barriers these individuals and communities face. Native people have a high rate of contracting HIV through injection drug use² and in the context of the current opioid epidemic, this is only worsening. Pre-exposure prophylaxis is a strategy that has the potential to combat these statistics.

PURPOSE

PrEP, or pre-exposure prophylaxis, is more than a pill. It is indeed a medication that when taken regularly and correctly can effectively prevent the acquisition of HIV. However, it is also a practice

built on a strong foundation of connections that span clinics, homes, cultures, and communities. It is not merely a medical transaction, but a strategy that requires trusting relationships between people and the constellation of communities that seek to support them. However, stigma and discrimination make PrEP, and all of its social and behavioral connotations, a difficult topic to discuss and a challenging strategy to implement. Organizations must recognize that there are cultural and historical considerations that impact Tribal communities’ ability to adopt PrEP, and social and systematic considerations that also present challenges. This toolkit explores the ways in which Tribes, Tribal organizations, community members, leaders, and service providers can foster the relationships and strengthen the systems needed to incorporate PrEP into medical practice, social norms, and community culture. It is meant to provide some tools, language, and conversation starters to begin bringing PrEP into a community.

This toolkit is intended to be used as a resource for Tribes, Tribal organizations and other entities seeking to partner with American Indian and Alaska Native communities to address HIV prevention integration and promote PrEP uptake – in both urban and non-urban areas. It is important

1 <https://www.ihs.gov/hiv/aid/hivaian/>

2 <https://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-report-2017-vol-29.pdf>



to keep in mind that this work and its lessons may look different across Tribal communities and health systems.

This toolkit is a starting point for: learning the basics of PrEP; exploring barriers and potential solutions to the uptake of PrEP; and incorporating PrEP into communities and practices. It can be used to inform conversations and interactions with the persons being served, or to start an open dialogue among Tribal leaders and members. The resources included are meant to help structure discussions, and develop action steps for integrating PrEP into Tribal communities.

LANGUAGE AND TERMINOLOGY

This toolkit addresses topics that are commonly stigmatized or considered taboo in many Tribal communities, such as sex, sexuality, substance use and disease, as well as populations that are often marginalized (people living with HIV, people that use drugs, transgender individuals, and homeless people, just to name a few). In order to honor those people who are referred to, this toolkit contains some important considerations for language and vocabulary below. Furthermore the toolkit seeks to model strengths-based,

person-first, and destigmatizing language throughout. Language is always evolving, and so does use, applicability, and understanding of its power. While these considerations can serve as guidance, it is impossible to completely include and consider specific examples from all cultures, contexts, populations and regions. It is always important to actively seek to contextualize the following principles and considerations to the populations being served, or are being sought to work with.

- 1. People-first language** aims to make personhood the essential characteristic of every person. People-first language views other descriptive social identities that people may hold as secondary, rather than using a term that makes a person's entire identity depicted by their behavior or other characteristics. For example, persons who use substances vs drug users; or even as simple as saying "person" or "community member" vs "patient" or "client." Another example, is saying "People with HIV" rather than "HIV Positives."
- 2. Strengths-based language** seeks to take a more positive approach to a topic by addressing those aspects or factors that empower or could enable a person or community to make change. This approach is particularly important for work within HIV and related



areas — an area that is often inundated with stigma and negative connotations. A strengths-based approach continuously looks for a more affirming perspective, and brings to light more positive aspects of an issue or concern that might not have been considered before. It relies upon identifying sources of resiliency and emphasizing opportunities for growth. For example, if during a discussion with a person who might benefit from using PrEP they say that they don't know if they would be a good candidate because in similar situations they have forgotten to take their daily vitamins every once in a while (deficit-based statement), a strength-based approach take the same scenario and looks for the strengths found. A provider could identify the strengths of the person and highlight them. It could look like saying “the fact that you have made a decision to take daily vitamins says you care about your health. In addition, despite the fact that in few occasions you have forgotten to take your vitamins, you continue to take them and don't give up. It says how much you care about staying on track to take care of you”.

- 3. It is also important to use destigmatizing language**, such as “healthier decisions” rather than “safer decisions;” the term reflects a risk involved and when talking with discordant couples, using the phrase “safer decisions,” might be interpreted as the person with HIV as being a risk to their partner and could affect their relationship.
- 4. All HIV programs should use accurate and well-defined language.** Words like exposure, transmission, medication are all common place in the HIV lexicon. Moreover, there have been recent advancements in HIV treatment and prevention science that have created new phrases — “undetectable = untransmittable”, and “PrEP” are just two examples. A provider — whether a medical service provider or a provider of other HIV services — needs to be sure that all language that is used is used correctly and completely understood by all parties. Below is a glossary that will help with this. For example, all providers should ensure that all parties completely understand what is medically meant by the term “undetectable” before disseminating messages that contain the word.



GLOSSARY AND ACRONYMS

Below is a list of terms and acronyms that are used throughout the toolkit — while this list is not comprehensive, it provides an overview of major terms.

Medical Terms

ART: Anti-Retroviral Treatment — ART is a combination of drugs that slows the progression of HIV by reducing the amount of virus (the “viral load”) in a person with HIV.³

HIV: Human Immunodeficiency Virus — HIV is a virus that attacks the body’s immune system, specifically CD4 cells, also called T cells. Over time, HIV can wipe out so many of these cells that the body can no longer fight off infections. HIV can only be spread through certain body fluids, such as blood, semen, and vaginal fluids.⁴

nPEP: Non-Occupational Post Exposure Prophylaxis — nPEP refers to short-term treatment started as soon as possible after high-risk exposure to an infectious agent, such as HIV, hepatitis B, or hepatitis C.⁵

PEP: Post Exposure Prophylaxis — PEP means taking antiretroviral medicines after being potentially exposed to HIV to prevent becoming infected. PEP should be used only in emergency situations and must be started within 72 hours after a recent possible exposure to HIV.⁶

PrEP: Pre-Exposure Prophylaxis — PrEP is when people at a very high risk for getting HIV take a daily medicine that reduces their risk of getting the infection.

STI: Sexually Transmitted Infection — Also known as sexually transmitted diseases (STDs), STIs are a group of conditions that are passed from one person to another through intimate physical contact.⁷

Individual and Behavioral Terms

HIV Tester: an individual who provides HIV and STI testing, screening, and sometimes education. (This is the preferred term to replace HIV Counselor.)

IDU: Injection Drug Use (This acronym is appropriate only when the U is used as a verb, and not as a person, (use vs user).)

3 <https://www.cdc.gov/hiv/basics/pep.html>

4 <https://www.cdc.gov/hiv/basics/whatishiv.html>

5 <https://aidsinfo.nih.gov/understanding-hiv-aids/glossary/3315/non-occupational-post-exposure-prophylaxis>

6 <https://www.cdc.gov/hiv/basics/pep.html>

7 <https://www.cdc.gov/std/general/default.htm>



LGBTQ+: Lesbian, Gay, Bisexual, Transgender, Queer, + includes intersex, questioning, and allies. Providers should look to their local community to determine the proper and locally accepted terminology.

LGBTQ2S: Lesbian, Gay, Bisexual, Transgender, Queer, and Two Spirit. There are other acronyms that refer to the larger gay or lesbian and related communities as well and include other groups like allies, asexual, pansexual, questioning individuals, as well. Just as with LGBTQ+, providers should look to their local community to determine the proper and locally accepted terminology.

Licensed PrEP Prescriber: A professional who is authorized to prescribe PrEP; these individuals are not always doctors.

MSM: Men Who Have Sex with Men

OD, SUD: Opioid Use Disorder, Substance Use Disorder

PrEP participants: clients, patients, and community members

PWID: Person Who Injects Drugs (This is the preferred acronym to replace IDU)

Two Spirit: This is a term that was born of a reclamation of Indigenous gender, sexual, and cultural identities and the collective action taken by these people to honor these identities and their traditional roles in their communities. Depending on the community, Tribe, village or Indigenous group, the term may have different meanings, or may actually be rejected altogether. In general, the term describes an American Indian or Alaska Native individual who is male-bodied or female-bodied, with a masculine or feminine essence, and any combination thereof. Two Spirit people can cross social gender roles, gender expression, and sexual orientation. Different Tribes may have their own language and terms for Two Spirit people.⁸

U=U: Undetectable = Untransmittable. CDC describes that people with HIV who take HIV medicine as prescribed and achieve and keep an

⁸ https://www.ihs.gov/sites/telebehavioral/themes/responsive2017/display_objects/documents/slides/lgbt/lgbtnativeout.pdf



undetectable viral load (or stay virally suppressed) have effectively no risk of transmitting HIV to their HIV-negative sexual partners.⁹ In early 2016, the Undetectable = Untransmittable (U=U) slogan was launched by the Prevention Access Campaign to promote the finding.

Organization Acronyms

CDC: Centers for Disease Control and Prevention

FDA: Food and Drug Administration

HRSA: Health Resources and Services Administration

IHS: Indian Health Service

NIHB: National Indian Health Board

SAMHSA: Substance Abuse and Mental Health Services Administration



⁹ <https://www.cdc.gov/hiv/risk/art/index.html>



2. What is PrEP?

Pre-exposure prophylaxis, or PrEP, is an HIV-prevention method through which people who do not have HIV take a daily medication that reduces their risk of getting the virus in case they may be exposed. PrEP is only for people who do not have the virus already. Studies have shown that PrEP can reduce an individual's risk of getting HIV from sex by more than 90% when taken daily; among people who inject drugs, PrEP can reduce the risk of getting HIV by more than 70% when taken daily.

Currently, there are two FDA-approved medications for PrEP: Truvada™ and Descovy.¹⁰ Both are pills taken once daily, and combine two anti-HIV drugs: Truvada™ is made up of emtricitabine and tenofovir disoproxil fumarate, and Descovy includes emtricitabine and tenofovir alafenamide. Truvada™ has been used for PrEP since 2012, and Descovy was approved for PrEP in October 2019. Both pills reduce the rate of HIV-1 infection in applicable groups at a similar rate. However, Descovy has not been indicated in individuals at risk of HIV-1 infection from receptive vaginal sex because the effectiveness in this population has not been evaluated.

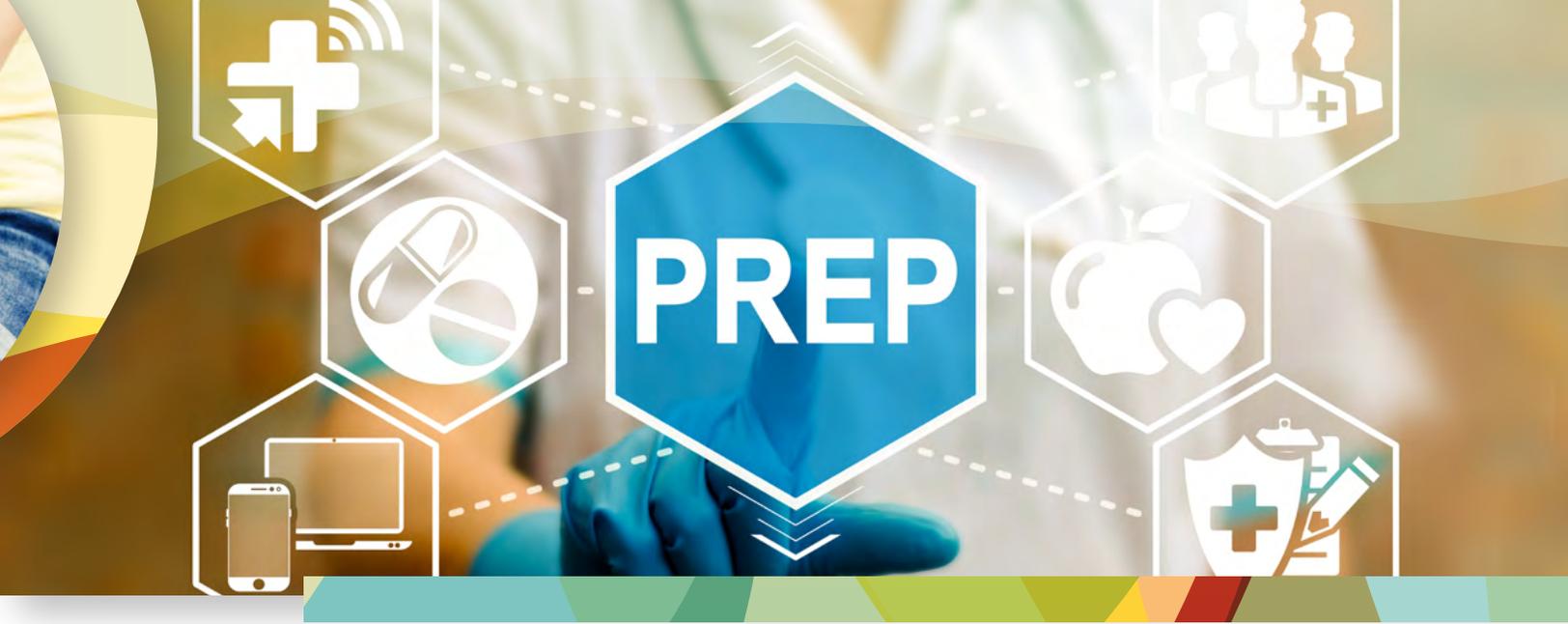
No significant health effects have been seen in people who are HIV-negative and have taken Truvada™ for up to five years. The only side effects are those already indicated and associated with the medication (i.e. heartburn, nausea, problems with sleeping, rash, and anxiety). Some individuals taking PrEP may experience less serious side effects, such as nausea, and most side effects go away with time.

It is important to note that PrEP only works to prevent HIV — not other sexually transmitted infections (STIs) or other types of infections. It should be used as part of a broader HIV prevention strategy which includes safer sex practices such as consistent and correct condom use.^{11 12}

10 <https://www.descovyhcp.com/discover-clinical-trial>

11 <https://www.cdc.gov/hiv/basics/prep.html>

12 <https://www.hiv.gov/hiv-basics/hiv-prevention/using-hiv-medication-to-reduce-risk/pre-exposure-prophylaxis>



Who should take PrEP?

It is intended for people who test negative for HIV (are not living with the virus) and adolescents who are at increased risk for getting HIV, be it through sex or injection drug use. Generally, PrEP benefits:

- Gay/bisexual men or men that have sex with other men that:
 - » Have a partner who is living with HIV, or a partner whose HIV status is unknown
 - » Have multiple partners, or a partner with multiple partners
- Heterosexual individuals who:
 - » Have a partner who is living with HIV, or a partner whose HIV status is unknown
 - » Have multiple partners, or a partner with multiple partners
- People who inject drugs and:
 - » Share needles or drug using equipment to inject drugs
 - » Are at increased risk for getting HIV from sexual activity

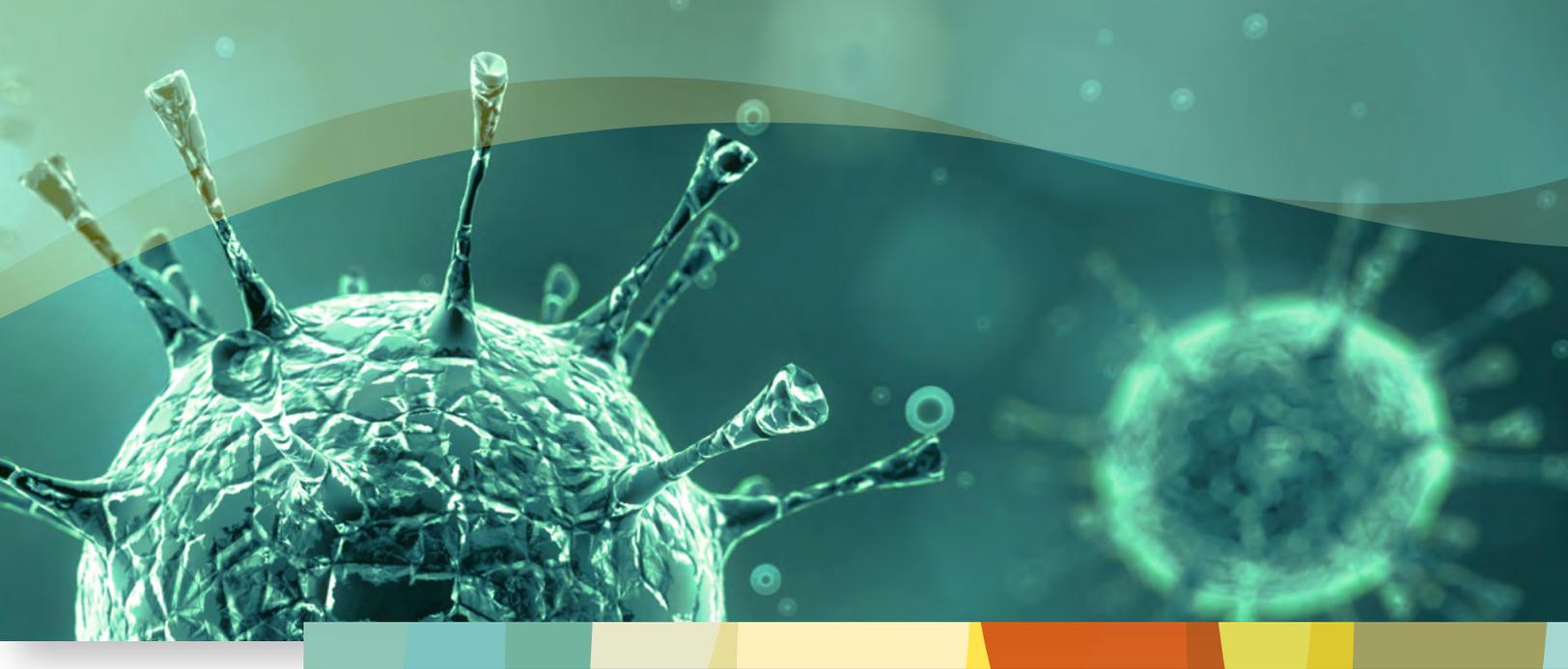
There is more information and guidance on how to identify candidates for PrEP in Section 4 of this toolkit.

3. Tribal Communities and PrEP



INTEGRATING PREP SERVICES INTO EXISTING TRIBAL AND TRIBAL ORGANIZATIONS' SERVICES

Even though deaths related to HIV have gone down, diagnoses of HIV among AI/AN have increased. PrEP prescribers must be prepared to answer critical questions that people may ask, such as “Would PrEP interact with traditional medicine?” or “Would PrEP interfere with my hormone treatment?” This presents a unique opportunity to communicate openly and honestly with people seeking services about the treatments and what is feasible and realistic for them. This does require that medical providers talk to practitioners of traditional medicine and learn how PrEP may or may not interact with traditional medicines. This is a key opportunity for medical providers to educate traditional practitioners about PrEP and HIV as well — to have conversations with them about what PrEP is and how it can benefit the community and enhance the holistic healing of the person in addition to the healing that they provide in their role.



When facilitating these conversations, it must be done in a way so that everyone learns about PrEP, has the opportunity to ask questions, and support each other's efforts.

Additionally, it is important to consider what organizations should know about integrating PrEP services into their current services, such as Insurance, Medicaid, protocols, state laws, Tribal governance, etc. If possible, looking at local trends in data and information can help to identify areas.

There are many opportunities for a Tribe or Tribal organization to integrate PrEP into other aspects of life that can help increase acceptance and normalize its use in Tribal communities. This includes increasing awareness of PrEP through normalized conversations with all clients, promoting PrEP through social media channels, educating staff about the pros and cons of talking about PrEP with the persons they interact with, partnering with clinicians who already prescribe PrEP, partnering with medical providers who might be interested in prescribing PrEP.

Cultural variations among American Indian and Alaska Native communities must be considered, particularly regarding the impacts of geography, assimilation, colonization, and cultural histories. All the cultural aspects that support the use of PrEP must be considered; this includes the traditional value of health, the notion passed down to generations to take medicine in order to help their bodies stay healthy, understanding how being a healthy individual contributes to a healthier community, and how PrEP contributes to a holistic sense of well-being in Tribal communities. In addition, having this understanding can also help to shape some prevention messages and uptake campaigns for PrEP. Providers can also integrate these messages and perspectives into conversations providers have with community members and the people they serve.

During interviews conducted in 2019 with various community members and providers, crucial information related to the integration of PrEP services into existing services was identified. The following recommendations and perspectives can support effective PrEP services.



Interview with Jonathan Iralu, MD, infectious disease consultant for the Indian Health Service, who practices medicine at the Gallup Indian Medical Center in Gallup, New Mexico. He is currently licensed to practice medicine in New Mexico:

PrEP education can be integrated into existing services and systems. Dr. Iralu gave the example of a Navajo Nation movie theater, which ran an ad for multiple years in the Navajo language promoting getting tested for HIV:

“*[The] company that owns theatres around here...does not like anything to do with sex, HIV, etc., but they were OK [with running the ad] if it was in the Navajo language.*”

Dr. Iralu mentioned that Navajo PrEP services are integrated into 5 of the 8 service units on the Navajo reservation: his team offers PrEP — primarily to young MSMs — and helps to operate a clinic serving transgender people in Gallup. He also mentioned that almost all of their services and information address PrEP and HIV care. His clinic has a strategy to increase access to PrEP by leveraging the power of word of mouth. Additionally, they use social media to boost their efforts. Specifically, they have created pop-up ads for Grindr with messages such as “My boyfriend is on PrEP and I want to be on it.” Participants are invited to click on the ad to get more information. He indicated that this is one of the most effective channels to bring more patients into the STD clinics. If someone is diagnosed with an STD, they are then referred to Dr. Iralu’s clinic. This is where they get most of their referrals. Lastly, as they serve persons with HIV, they are aware of the U=U campaign and want their patients’ partners to be on PrEP.



Interview with a PrEP user from the Cherokee Nation:

When it comes to educating peers on PrEP, the interviewee emphasized the importance of assuring that this information comes from Native voices. Communities will only begin to accept the use of PrEP if its integration comes from within the community itself.

“ *It is important for Natives to teach Natives... Native people are definitely at risk [for HIV], so they need to make different [educational] materials for different people.”*

Integrating existing cultural practices and philosophies into educational materials is key for presenting PrEP to members of the intended

population. Individuals are more likely to identify with and trust the content in such materials when they see people that think, talk, and look like them.

This interviewee also spoke to the preventative benefits that PrEP provides. It is a reassurance, a tool that individuals can use to protect and take care of themselves.

“ *PrEP is HIV preventative — 96% effective. If you use it regularly, it is successful as it should be. I thought this [PrEP] is something I should get on, because it will keep me safe. Helps me keep a sane state of mind whenever I am hooking up.”*



HOW IHS SUPPORTS TRIBES AND TRIBAL ORGANIZATIONS ADOPTING PREP SERVICES

The IHS HIV/AIDS Program aims to reduce the number of new HIV infections annually, ensure access to and quality health services for individuals with HIV and those at risk, and to create sustainable programs of HIV prevention and treatment in Tribal communities. While it does not have a separate line item budget for HIV treatment and prevention services, IHS encourages the health centers it funds to integrate PrEP and HIV prevention services into their systems. Each year, it may have the opportunity to fund specific projects, but these vary each year.¹³

It is important for Tribes, Tribal organizations and providers serving AI/AN communities to note that in August 2018, the Indian Health Service National Pharmacy and Therapeutics Committee (NPTC) added Truvada™ to the formulary as a pre-exposure prophylaxis against HIV infection. Previously,

Truvada™ existed in the formulary for HIV post-exposure prophylaxis (PEP) only. As of December 2019, Descovy has not yet been added on the National Core Formulary.¹⁴

IHS has developed a number of resources that Tribal communities can use to start conversations around adopting PrEP services into the care available to community members.

- **General HIV Training.** IHS offers a series of training modules that blend the work of the National HIV/AIDS Program, community members, and Traditionalists from across the country. There are modules for providers, as well as community members. Please visit <https://www.ihs.gov/hiv aids/training/> to access these modules.
- **Tribal HIV/STD Advocacy Kit and Policy Guide: A Kit for American Indian and Alaska Native Tribal Leaders, Health Advocates, and Decision-Makers.** This advocacy kit is designed to help Tribal health advocates and

¹³ <https://www.ihs.gov/hiv aids/faqs/#q4>

¹⁴ https://www.ihs.gov/sites/nptc/themes/responsive2017/display_objects/documents/guidance/NPTC-Formulary-Brief-HIV-PrEP.pdf



decision-makers address sexual health challenges in their communities through programmatic and policy changes. https://www.ihs.gov/sites/hivaids/themes/responsive2017/display_objects/documents/tribalpolicy_kit.pdf

- **Tribal HIV/STD Advocacy Kit and Policy Guide.**

Created by the Indian Health Service, with assistance from the Office of Minority Health Resource Center and the Northwest Portland Area Indian Health Board. This kit highlights steps that organizations can take to promote sexual health and wellbeing in Tribal communities, activities and interventions, and policy steps: https://www.ihs.gov/sites/hivaids/themes/responsive2017/display_objects/documents/trainingkitinfo.pdf

- **Tribal HIV/STD Policy Templates Toolkit.**

This kit provides policy templates related to enhancing Tribal sexual health and HIV/STD prevention, implement HIV/STD reporting guidelines, implementing universal HIV testing and STD screening: <https://www.ihs.gov/sites/>

[hivaids/themes/responsive2017/display_objects/documents/trainingkit_templates.pdf](https://www.ihs.gov/sites/hivaids/themes/responsive2017/display_objects/documents/trainingkit_templates.pdf)

- **PrEP Education Flipchart.** A tool that captures information about PrEP education under the understanding of treatment as prevention. It is divided by sections geared towards potential PrEP users and towards the provider: https://www.ihs.gov/sites/hivaids/themes/responsive2017/display_objects/documents/prepflipchart.pdf



4. Who May Use PrEP?

WHO SHOULD PRESCRIBE PREP?

Medical providers who see people at increased risk of HIV on a routine basis should consider becoming an active prescriber that can offer PrEP. To be more specific, any clinician or medical provider licensed to prescribe medications can also prescribe PrEP. They will need to learn about the medication, how to identify if PrEP is appropriate for the people they see, benefits, costs, side effects, and the specific laboratory tests required, etc. This means that case managers, HIV testing staff and navigators are in a unique position. Although they are not licensed to prescribe medication, they are often the first contact for clients who may be eligible for PrEP. They are in a position to intervene and counsel the PrEP eligible partners, and make the referrals to licensed medical providers. It is also important to highlight that adoption of PrEP among non-prescribing providers has been slow. In a study published in 2019 among HIV case managers and rapid testers where PrEP eligibility screening was part of rapid HIV testing at their organization, 40% never had PrEP training and only 27% indicated personally screening clients for eligibility regardless of their positive

attitudes about PrEP and perceived organizational support. This study highlights the importance of training non-prescribing HIV prevention providers about PrEP, addressing their concerns, and incorporating PrEP screening and referral into routine HIV testing as part of the PrEP pre-implementation practices.¹⁵

The *Comprehensive Guidelines for Prescribing PrEP*¹⁶ can help to identify who may benefit from the use of PrEP. CDC has published this document, which includes *Guidelines in Clinical Practice and Clinical Providers' Supplement*.¹⁷

The *Clinical Providers' Supplement* contains additional tools, such as:

- A patient/provider checklist
- Patient information sheets
- Provider information sheets
- A risk incidence assessment
- Supplemental counseling information
- Billing codes, and
- Practice quality measures.

15 <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0223486>

16 <https://stacks.cdc.gov/view/cdc/20711>

17 <https://www.cdc.gov/hiv/pdf/risk/prep/cdc-hiv-prep-provider-supplement-2017.pdf>



Questions or advice related to prescribing PrEP, can be directed to the National Clinicians Consultation Center PrEP Line at 1-855-448-7737 (11:00 AM - 8:00 PM EST).

The Indian Health Service has also released additional educational HIV and PrEP materials that can serve as helpful resources for providers – both new and experienced.¹⁸ Included in this is the PrEP ECHO that was launched in early 2020. The 6 session, virtual training curriculum provides comprehensive information for clinicians to end the HIV epidemic and effectively integrate and improve PrEP services in Indian Health Service, Tribal, and Urban Indian clinics. Continuing education credits are provided. More information can be found at: <https://indiancountryecho.org>.

IDENTIFYING CANDIDATES FOR PREP INITIATION

Using antiretroviral medications, such as PrEP, is an evidence-based way to prevent new infections. Anyone who would like protection from HIV can use PrEP. CDC states that it is the most effective among persons at greatest risk, and that it is important to consider PrEP as part of a comprehensive prevention plan that includes a discussion about medication adherence, condom use, and other risk reduction methods. PrEP is intended and most effective for persons without HIV who are at an increased risk for acquiring HIV. That includes individuals who engage in sexual relationships with infrequent condom use with persons with HIV or with unknown status, and persons who inject substances (hormones, legal or illegal substances, etc.). Because PrEP is a daily pill, it is most effective for persons who are committed to medication adherence.

The following *PrEP 101*¹⁹ information sheet developed by CDC provides basic information and resources related to PrEP.

18 <https://www.ihs.gov/navajo/healthcarefacilities/gallup/>

19 <https://www.cdc.gov/hiv/pdf/library/factsheets/prep101-consumer-info.pdf>

PrEP 101

Are you HIV-negative but at very high risk for HIV? Taken every day, PrEP can help keep you free from HIV.

What Is PrEP?

- PrEP, or pre-exposure prophylaxis, is daily medicine that can reduce your chance of getting HIV.
- PrEP can stop HIV from taking hold and spreading throughout your body.

- Daily PrEP reduces the risk of getting HIV from sex by more than 90%. Among people who inject drugs, it reduces the risk by more than 70%.
- Your risk of getting HIV from sex can be even lower if you combine PrEP with condoms and other prevention methods.



Is PrEP Right For You?

PrEP may benefit you if you are HIV-negative and **ANY** of the following apply to you.

You are a gay/bisexual man and

- have an HIV-positive partner.
- have multiple partners, a partner with multiple partners, or a partner whose HIV status is unknown—and you also
 - have anal sex without a condom, or
 - recently had a sexually transmitted disease (STD).

You are a heterosexual and

- have an HIV-positive partner.
- have multiple partners, a partner with multiple partners, or a partner whose HIV status is unknown—and you also
 - don't always use a condom for sex with people who inject drugs, or
 - don't always use a condom for sex with bisexual men.

You inject drugs and

- share needles or equipment to inject drugs.
- recently went to a drug treatment program.
- are at risk for getting HIV from sex.



Visit Your Healthcare Provider

- To find out if PrEP is right for you.
- Every 3 months, if you take PrEP, for repeat HIV tests, prescription refills, and follow-up.
- If you have any symptoms while taking PrEP that become severe or don't go away.
- If you don't have a provider, visit <https://prelocator.org> to locate one.



How Can You Get Help To Pay For PrEP?

- Most private and state Medicaid plans cover PrEP. If you are on Medicaid, check with your benefits counselor.
- If you have health insurance, you may receive co-pay assistance from drug manufacturers or patient advocacy foundations.
- If you are without medical insurance, consider enrolling in an insurance marketplace, manufacturer patient assistance program, or your state's Medicaid plan, if you are eligible for it.
- Learn more about paying for PrEP at www.cdc.gov/hiv/pdf/risk/prep/cdc-hiv-paying-for-prep.pdf.

For more information please visit www.cdc.gov/hiv

National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention
Division of HIV/AIDS Prevention





OBTAINING PREP

Persons have access to PrEP through prescription only — so, they must talk to a provider in order to receive the medication. It is important to note that different states, clinics, or Tribal health systems may have different prescribing guidelines for PrEP. The standard recommendation is to have conversations about PrEP prior to referring the person to a provider. The Tribe or organization then refers the person to a PrEP provider, and then the person receives PrEP through a pharmacy — just like any prescription.

Additionally, and in order to increase PrEP uptake, some states are easing the process and in some cases, the restrictions. For example, recent California legislation is making it possible for individuals to receive 60 days of PrEP without a prescription. Pharmacists will be able to provide individuals with PrEP if they have tested negative for HIV in the past week. California is the only state so far to enact such policy.²⁰ Those obtaining services and medication within the I/T/U system should be able to access the IHS Core Formulary (which contains PrEP medication). For those using private insurance or other coverage methods, the cost of PrEP is covered by many health plans. Medicare and Medicaid coverage may include PrEP,

however this is determined at the state level, and so prescriber and Medicare or Medicaid enrollees should ask their state office to see if the medication is covered. For those who have limited income or no coverage or insurance, there are medication assistance programs (through pharmaceutical companies, state health or local departments, or private entities) in place to provide PrEP free or at reduced-cost. Organizations and Tribes can learn more about PrEP assistance programs here: <https://www.nastad.org/prepcost-resources/prep-assistance-programs>. It is important to highlight that without insurance, out-of-pocket costs can be as high as \$13,000 per year.²¹ In addition, the *Are You Insured to Cover Your Costs for PrEP*²² chart might help community members navigate how to obtain PrEP through private insurance

For these reasons, the **Ready, Set, PrEP** program was established in early 2020. Ready, Set, PrEP is a nationwide program led by the U.S. Department of Health and Human Services (HHS). The *Ready, Set, PrEP* program provides pre-exposure prophylaxis (PrEP) medications at no cost to thousands of individuals who qualify.

The Ready, Set, PrEP website has more information to determine eligibility for this initiative.

20 <https://www.nytimes.com/2019/10/09/us/california-hiv-drugs-prep.html>

21 <https://prepfacts.org/prep/the-questions/>

22 http://www.floridahealth.gov/diseases-and-conditions/aids/prevention/_documents/PrEP-toolkit.pdf

ARE YOU INSURED TO COVER YOUR COSTS FOR PrEP?

You can also use www.prepcost.org to calculate your costs.



projectinform.org/prep-chart
Updated: January 10, 2019

YES

(employer, private, insurance marketplace, COBRA, Medicare, Medicaid)

1

Gilead Advancing Access Co-pay Card
gileadcopay.com
877-505-6986

- \$7,200 max/calendar year
- No income limit
- Covers co-pays, deductibles and co-insurance
- Re-apply annually as needed
- US resident
- Not available for persons with Medicaid, Medicare, VA or other state/federal prescription drug programs

If pharmacy cannot process Gilead's Co-pay Card, keep sales and pharmacy receipts. Call number on back of co-pay card. Submit paperwork for reimbursement for all refills. Terms, conditions at gileadcopay.com.

2

Patient Access Network Foundation
panapply.org
866-316-7263

- \$4,800 initial grant, up to \$8,000 max/year, re-apply
- Income <500% FPL (\$60,700)
- Based on taxable income (1040 line 7, 1040 EZ line 1)
- Medicare plans only
- Covers co-pays, deductibles and co-insurance
- US resident
- Pharmacies can bill PAN Foundation directly

These programs may be subject to funding shortfalls, which may limit enrollment.

3

Patient Advocate Foundation (PAF)
tinyurl.com/PAFhelp, or copays.org

- \$7,500 max/year, re-apply
- Income <400% FPL (\$48,560) + COLI (cost of living index) adjustments
- Based on taxable income (1040 line 7, 1040 EZ line 1)
- Must be insured (as listed under "YES" above)
- Covers co-pays only
- Proof of US residence (utility bill, etc.)
- Case managers available to help (800-532-5274)

FSA (flexible spending account)

Employer FSAs can help cover up to \$2,700 of out-of-pocket costs.

If you're a resident, these state plans may also help if you're insured or uninsured:

- CALIFORNIA: tinyurl.com/CAprepAP
- COLORADO: tinyurl.com/COprepFAP
- ILLINOIS: tinyurl.com/ILprepAP
- MASSACHUSETTS: crine.org/prepdap (cost of drug, services)
- OHIO: tinyurl.com/OHprepPAPI (cost of services)
- NEW YORK: tinyurl.com/NYprepAP (cost of services)
- VIRGINIA: tinyurl.com/VAprepDAP
- WASHINGTON: tinyurl.com/WAprepDAP (cost of drug)

NO

U.S. RESIDENT?

NON-RESIDENT/
UNDOCUMENTED?

What's the date?

dates may differ in some states

NOV 1 – DEC 15

Enroll in an insurance marketplace
tinyurl.com/stateACAplans

Avoid Bronze plans if you can: they generally have higher costs. Silver plans will offer lower costs for people earning up to 250% FPL (\$30,350). Gold & Platinum plans offer better coverage if you can afford them. Carefully select the right plan for you.

Special enrollment

You can get insurance at other times for "qualifying life events" such as: pregnancy, loss/change of job, change in household size, change in income, recent move, change in citizenship.

dates may differ in some states

DEC 16 – OCT 31

below 138% FPL / yr
(< \$16,754)

above 138% FPL / yr
(> \$16,754)

What's your income?

below

Enroll in the Gilead MAP.
www.truvada.com/
truvada-patient-
assistance

above

Retail cost of Truvada

500% FPL
(2018 FPL: \$12,140
taxable income + \$4,320
per dependent, higher
FPL% in Alaska and Hawaii,
1040 tax form line 7,
1040 EZ line 1)
— only cost of drug —
tinyurl.com/FPLincomes

Find a public clinic (FQHC) that serves undocumented patients. (findahealthcenter.hrsa.gov)

Check if you can get insurance through marketplace/employer.

IF NO

RECOMMENDING PREP

This is a short list of considerations that can help staff members determine if PrEP would be helpful for a particular member of the communities they serve. This includes considering if the person mentioned any of the following during conversations:

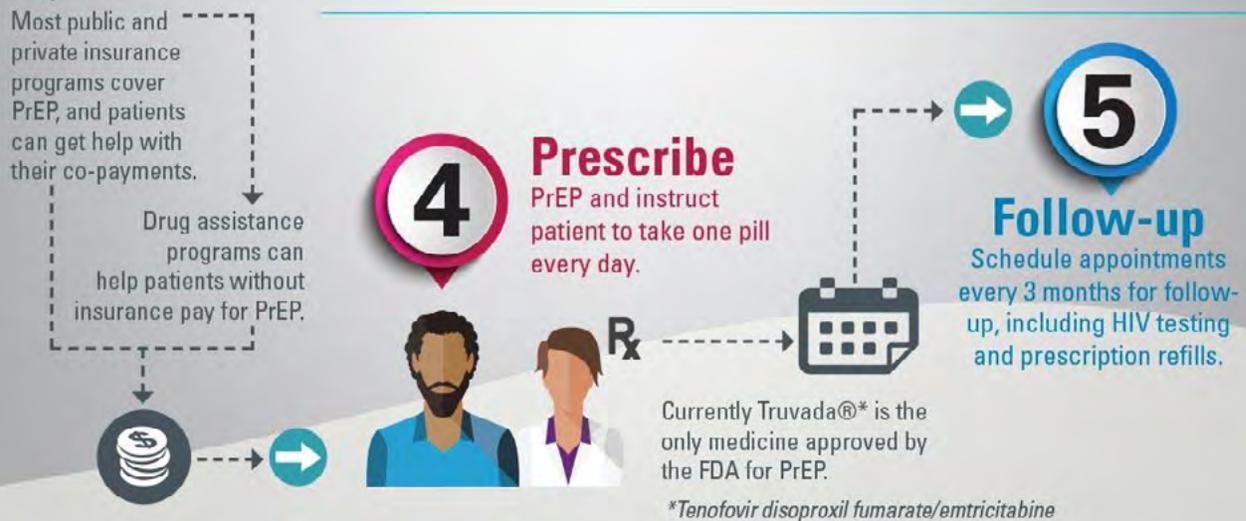
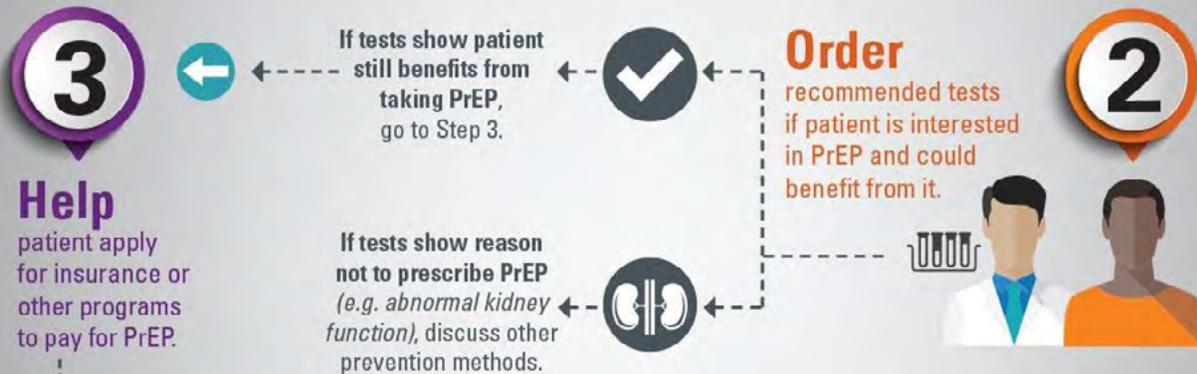
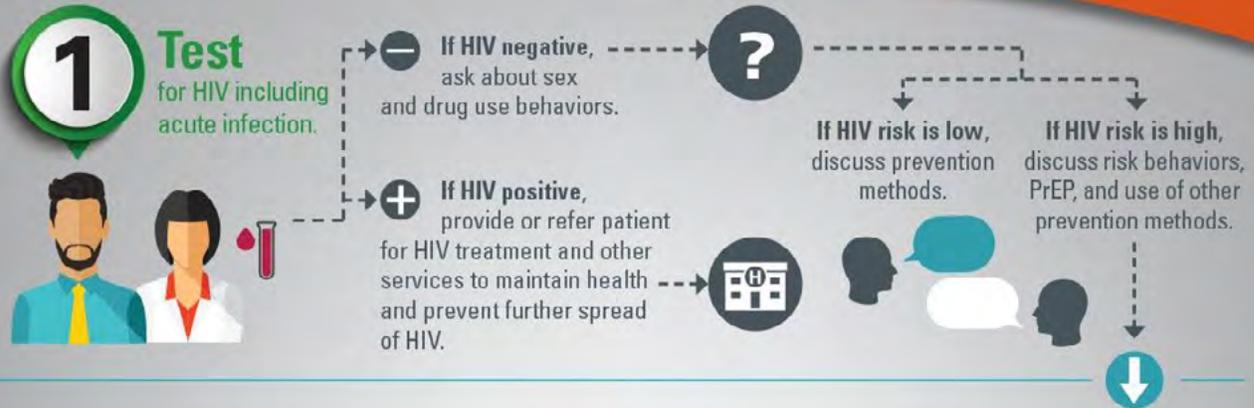
- Receiving an HIV negative test results in the last 6 months
- Having any sex partner in the last 6 months
- Being in a non-monogamous relationship
- Being in an ongoing sexual relationship with a person living with HIV
- Engaging in infrequent condom use during any anal or vaginal sex
- Having had a bacterial STI diagnosed or reported in the past 6 months
- Using drugs
- Being successful with daily habits

WHO MAY NOT BE A GOOD CANDIDATE FOR PREP

PrEP is intended for persons without HIV at an increased risk for HIV acquisition, and is most effective when they take the pill every day as prescribed. For this reason, persons with HIV do not qualify for PrEP. Instead, they should be referred to a medical provider to help them initiate ART.

It is also important to note that individuals who struggle with keeping daily habits consistently might also struggle taking PrEP medication daily. The following PrEP infographic provides additional guidance to identify who is eligible for PrEP.

Any prescribing health care provider can deliver PrEP care.



SOURCE: 2014 PrEP Clinical Practice Guidelines.

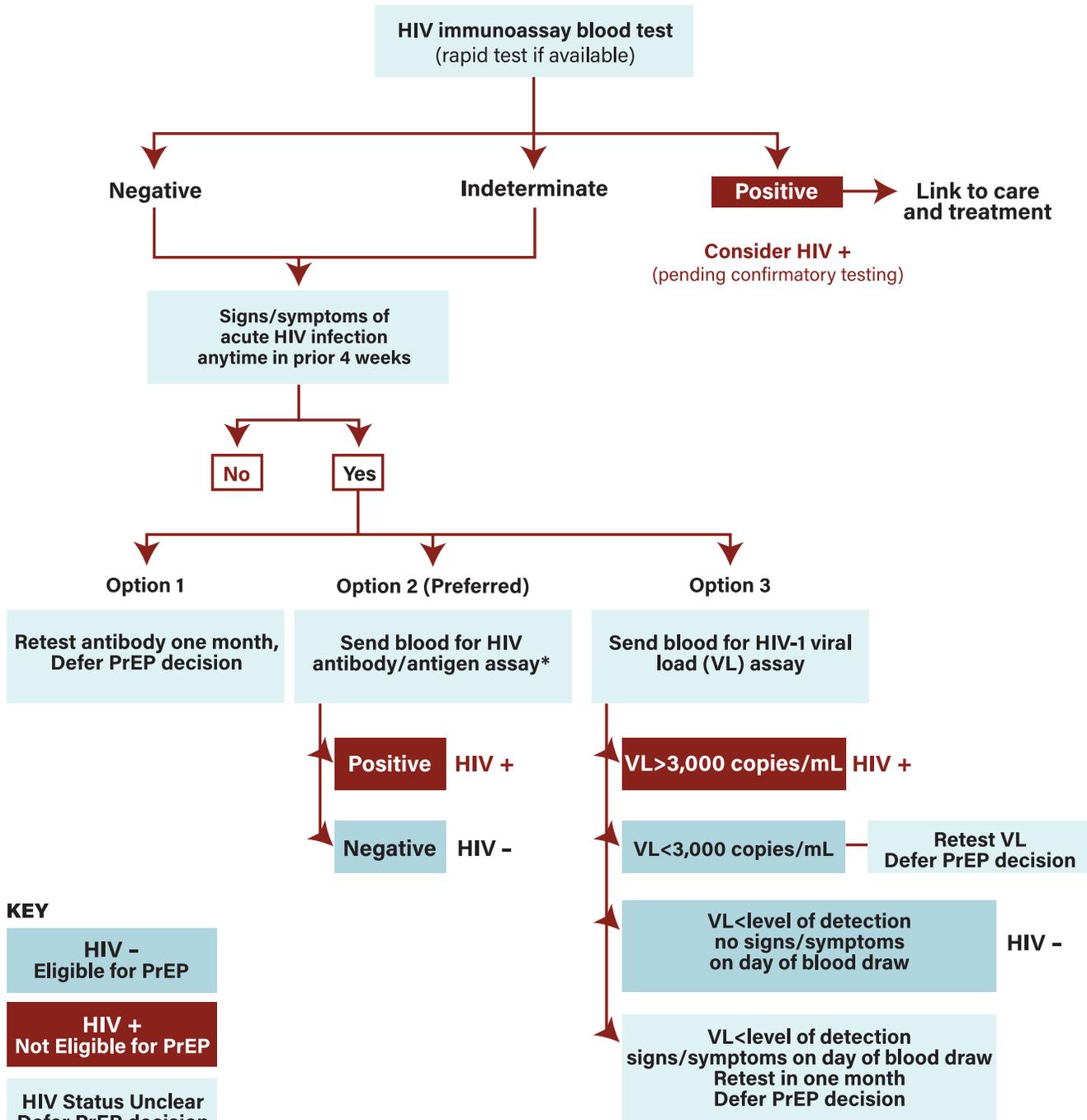
Have questions?

Read the full 2014 PrEP Clinical Practice Guidelines:
www.cdc.gov/hiv/pdf/PrEPguidelines2014.pdf

Call the PrEP Clinician Helpline:
 (855) 448-7737
 or (855) HIV-PrEP



HIV Status Algorithm



KEY

- HIV -
Eligible for PrEP
- HIV +
Not Eligible for PrEP
- HIV Status Unclear
Defer PrEP decision

* Use only HIV antigen/antibody tests that are approved by FDA for diagnostic purposes

GUIDE FOR TRIBES AND TRIBAL ORGANIZATIONS ON THE INTEGRATION OF PREP SERVICES

How to talk to a community member about PrEP

If a Tribe or organization is providing information, services, and referrals related to PrEP, HIV testing, and other HIV prevention services, staff members may be interested in becoming an *HIV Prevention Certified Provider*.²³ There are various training events available to participate in. The CBA Provider Network funded by CDC offers this certification through online courses. More information about how to access this resources to obtain certification can be obtained from CDC Project Officers

One of the best times to discuss the need or interest in PrEP with a potential candidate is while conducting an HIV test following the CDC *HIV Testing Recommendations*.²⁴ During these sessions, testers can obtain a detailed sexual and drug use history to determine if the person is at increased risk of HIV acquisition and their willingness to adhere to taking a daily pill. Moreover, testers can let the person know that taking PrEP also requires participation in follow-up appointments with their PrEP prescriber to maximize adherence, and minimize barriers to adherence. Additionally, it can help the person understand that if PrEP is used inconsistently, it will not be effective in preventing HIV infection. Consistent use of PrEP, together with

other prevention methods (consistent condom use, discontinuing drug injection, or never sharing injection equipment) provides very high levels of protection.²⁵

If the person is interested in learning more about PrEP, information can be provided about what it means to commit to taking PrEP, its benefits and limitations, and cost as applicable. The attached *PrEP 101* has more information.²⁶

If a community member wants to try PrEP, what do they do next?

Tribes and Tribal organizations can recommend PrEP to any person who might need it; however, only licensed prescribers can prescribe PrEP. It is important to note that a specialization in infectious diseases or HIV medicine is not required. If an organization does not have a staff member licensed to prescribed PrEP, it can develop a relationship with clinics that do and refer the person to the clinician who can prescribe it. For this, organizations can leverage their referral policies and procedures, existing relationships with providers, and available technical assistance to develop a tailored plan to make effective PrEP referrals. Case managers and navigators can initiate the conversations and refer to the person's primary care providers to receive their prescription. It is recommended that these relationships with other providers are established before the organization begins their conversations about prep with people they serve.

23 <https://www.brainshark.com/brainshark/public/ssreg/register.asp?SSReg=1&UserId=8658209&CompanyId=2227843>

24 <https://www.cdc.gov/stophivtogether/library/hiv-screening-standard-care/brochures/cdc-lsht-hssc-brochure-clinical-resource-folder.pdf>

25 U.S. Public Health Service. (2014) Preexposure prophylaxis for the prevention of HIV infection in the United States – 2014: A clinical practice guideline. Retrieved from: <http://www.cdc.gov/hiv/pdf/PrEPguidelines2014.pdf>

26 <https://www.cdc.gov/hiv/pdf/library/factsheets/prep101-consumer-info.pdf>

Additionally, organizations must keep in mind that primary care providers who see members of populations at increased risk of HIV on a routine basis may be already having these conversations. They can offer and provide PrEP to all eligible individuals, and invite the person to discuss this option with their primary care provider. If members of an organization are licensed to prescribe PrEP, it is important to learn all about what it takes to prescribe PrEP. *Prescribe PrEP FAQ* is a helpful resource for this.²⁷

Staff member to-do list

1. Prepare for talking to community members about PrEP. Before recommending PrEP to anyone, a provider or public health professional should learn all that there is to know about the medication, treatment regimen and generally adopted recommendations. Prepare in advance by developing probing questions that you can ask people about their knowledge, interest, and qualifications about PrEP. You could ask questions such as:
 - Have you heard about PrEP before?
 - What do you know about PrEP?
 - Have you thought about taking PrEP?
 - Do you know anyone who is currently using PrEP?
 - How do you think PrEP could help you prevent HIV?
 - How do you feel about start taking PrEP?
 - What challenges do you think you could face from taking PrEP?
 - Do you know if your insurance covers PrEP?

Additionally, one of the major discussions that providers must have with persons interested in taking PrEP is a conversation about what to do when or if the person wants to stop using PrEP. Consider what the conversation with the person might look like, their reasons, their concerns, any concerns about resistance to the medication, and concerns about PrEP effectiveness if the person chooses to start it up again later. In addition, consider what the conversations between the person and their partner might look like so the staff member can provide guidance to the person.

2. Have materials, printed and otherwise, with information about PrEP in waiting areas, meeting room, and at desks. This includes posters, pamphlets, flyers, or videos. These could help visitors start thinking about PrEP before initiating a conversation. These materials could also fortify any supporting messages about using PrEP. A PrEP education video or public service announcement could also be playing on televisions in common waiting areas.
3. Identify champions in the community who are successfully taking PrEP — specifically members of the community that programs are aiming to reach and with whom clients could identify.
4. Ensure that intake forms or any other data collection materials capture information about recommending and referrals to PrEP. This includes having questions that ask about sexual and drug using behaviors, HIV and STI diagnosis and testing history, and sexual and drug use partners.

27 <https://www.cdc.gov/stophivtogether/library/prescribe-hiv-prevention/brochures/cdc-lsht-php-brochure-prep-faq.pdf>



GUIDE FOR COMMUNITY MEMBERS

It is also beneficial to develop a guide with materials and information about PrEP that individuals can take after PrEP has been discussed with them. When gathering materials or developing them, it is useful to include the information that speaks to the person interested in PrEP, such as:

1. What questions can you ask your provider that can help determine if PrEP would be beneficial for you. Briefly list the qualifications for PrEP in terms that the person could simply understand and use language that is supportive and destigmatizing, such as the following:
 - Why is being HIV negative important to me?
 - How much do I know about PrEP?
 - What would it take for me to start PrEP?
 - What would it take for me to be adherent to PrEP?
2. How to prepare for talking to a healthcare provider or licensed prescriber about PrEP. Briefly describe considerations a person should have to help them feel prepared to talk to their provider to talk about PrEP, such as the following:
 - What will it be like to talk to your provider about this?
 - What questions might you have for him/her?
 - How might you remember to ask specific questions?
 - How can you make talking to your provider as easy as possible?
 - What concerns you the most in talking to him/her?
3. How to talk to a provider or licensed prescriber about PrEP. Describe how a person could bring up the topic of PrEP and include a list of important questions the person could ask.
 - Consider initiating the conversation with your provider about PrEP by saying that you are interested in taking this pill.
 - Ask your provider if s/he can prescribe PrEP.
 - Ask your provider to share more information about the pill and if s/he thinks you qualify for PrEP.
 - Ask your provider if her/his office provides assistance in paying for PrEP.
 - Ask your provider to help you learn more about the side effects from taking PrEP.
 - Ask your provider what it takes to start and successfully take PrEP.
 - Ask your provider what you should know about stopping PrEP after you have initiated it.



4. What to do next if there is interest in starting PrEP? Briefly list the next steps a person could take to start PrEP, such as the following:
- Talk to your medical provider about initiating PrEP
 - Talk to your medical provider or insurance provider to make sure that PrEP can be obtained by the local pharmacy, or that state Medicaid or a private insurance plan will cover the cost of PrEP.

- Consult with a traditional practitioner to receive their guidance on taking PrEP.
 - Talk to someone you know who is taking PrEP about their experience, including the benefits and challenges they have experienced.
5. Provide a flowsheet of what it looks like to go on PrEP. You might want to develop a flowchart similar to *GETTING PrEPARED*²⁸

28 <https://www.thebodypro.com/article/flow-chart-for-accessing-prep-for-hiv-prevention>

5.3

GETTING PrEPPED

Some people may face problems with their insurance covering the costs of Truvada for PrEP. This infographic provides details that may be useful to you. Learn more about PrEP at these websites: ▶▶▶▶▶▶▶▶

CHECK YOUR INSURANCE PLAN

FIND A MEDICAL PROVIDER WHO SUPPORTS YOUR DECISION TO PrEP

MEDICAL VISITS, BLOOD WORK

GET YOUR PRESCRIPTION

PICK UP PRESCRIPTION

PAY FOR THE MEDICATION AND OTHER COSTS

Your costs

Check your insurance plan to see what you pay out of pocket (OOP) while on PrEP

- What is your deductible?
- What drug tier is Truvada on?
- What are your total costs for medical visits, blood work and prescriptions?
- What other OOP costs are you responsible for, such as co-insurance?
- Ask for help from your doctor's office, pharmacist, local case manager or insurance plan rep.
- Avoid Bronze plans if you can (they generally have higher OOP costs). If you can afford them, Silver, Gold and Platinum plans offer better coverage.

Schedule an appointment

Approach your medical provider about Truvada for PrEP prescription.

- If they will prescribe, GREAT NEWS!
- If they don't know about PrEP but are willing to prescribe:
 - 1) They can consult the Federal Guidelines: (tinyurl.com/2017PrEPguidelines), and/or
 - 2) They can consult the CCC's PrEPline at 855-448-7737 during business hours (tinyurl.com/CCCprepline), and/or
 - 3) They can consult NASTAD's "Billing Coding Guide for HIV Prevention" (tinyurl.com/NAStADguide).
- If they won't prescribe:
 - 1) Read/utilize these resource materials:
 - "Talk to Your Doctor": tinyurl.com/PrEPbrochureCDC
 - "Work through Doctor Visit": tinyurl.com/PrEPdocvisit
 - 2) Ask for a referral, or find another provider on your own:
 - your insurance plan's provider directory
 - public health clinics (findahealthcenter.hrsa.gov), STD clinics, Planned Parenthood (tinyurl.com/PPclinics)
 - local, county and state health departments
 - PrEP-friendly provider search engines:
 - ... pleasepreme.org/find-a-provider
 - ... preplocator.org
 - ... greaterthan.org/get-prep

If you encounter uncovered costs related to your care, these options may help:

Public health clinics

- Some public health clinics offer sliding fee scale for medical visits and blood work.

FSAs

- Flexible Spending Accounts are accounts set up with pre-tax dollars to help pay for OOP health care costs.
- FSAs have an annual limit of \$2,700, available through employers if offered.
- Enrollment is usually annual, so plan ahead.

Prior authorizations

Some insurance plans require a prior authorization (PA) for Truvada for PrEP.

- This is normal.
- May need extra paperwork.
- Your provider can use the codes found on p42 at tinyurl.com/2017PrEPsupplement.
- Re-submit paperwork until the PA is approved.

Denials

- Your provider should code paperwork correctly to your insurance carrier. (URL above.)
- Work with your provider's office to submit challenge(s). It may take more than one.

Tele-PrEP services

- Online resources may be able to prescribe PrEP to you without a doctor's visit in some states:
 - ... heyimstr.com
 - ... nurx.co/prep
 - ... prep.pushcare.com

Pharmacy refills

Plans vary in what they offer. Your plan may:

- Vary in how you get meds (at pharmacy, mail order).
- Provide only 30-day refills
- Offer 90-day refills
- Make you initiate the monthly refill
- Have an auto-send function for refills
- Offer refills earlier than waiting 30 days

ALSO:

- In-network pharmacies will reduce your cost.
- Apply for Gilead's Co-Pay Card **before** going to a pharmacy (next column).
- If pharmacy doesn't accept Co-Pay Card, keep pharmacy and sales receipts. Call the number on back of co-pay card. Submit paperwork for payment.

Manufacturer assistance

gileadadvancingaccess.com, 800-226-2056 (18 years or older)

Co-Pay Assistance

- covers up to \$7,200 per calendar year, out-of-pocket costs
- for commercially insured individuals, re-apply annually
- not available for persons with Medicaid, Medicare, VA or other federal/state prescription drug programs

Medication Assistance

- uninsured, insurance declined payment, or no pharmacy benefits
- US resident (SSN not required) and family income <500% FPL (federal poverty level, tinyurl.com/FPLincomes)
- eligibility confirmed every 12 months

Patient Access Network Foundation

- Medicare plans only; family income below 500% FPL
- \$8,000 max per year, may reapply
- Covers co-pays, deductibles and co-insurance
- panapply.org, 866-316-7263 (program is sometimes closed)

Patient Advocate Foundation

- Insured individuals only; family income below 400% FPL + COLI
- \$7,500 max per year for co-pay/deductible costs, may reapply
- tinyurl.com/PAHelp or copays.org or 800-532-5274

State assistance programs for residents of:

- California, Colorado, Illinois, Massachusetts, New York, Ohio, Virginia and Washington. Check other side for websites.

projectinform.org/prep

prepfacts.org

pleasepreme.org

nastad.org/prepcost

hiveonline.org

thewellproject.org/hiv-information/prep-women

whatisprep.org

facebook.com/groups/PrEPFacts

6. "I'm on PrEP, now what?" Briefly list important steps a person could take once they have initiated PrEP, such as the following. It is important to know some facts about being adherent to PrEP:

- PrEP is a pill that helps prevent HIV acquisition and in order to be effective, you must take every dose every day.
- It is important to combine PrEP with other prevention methods such as using condoms correctly and consistently and/or not sharing needles.
- It is recommended that once you initiate PrEP, you meet with your medical provider every six months to discuss how the pill is working for you, and how to address any challenges you might face in being adherent and to refill your prescription.

7. To help an individual learn what to expect when starting PrEP, it could be helpful to explain what happens to someone once they start taking it. This could include the following:

- Taking control of my sexuality and my health. I am responsible for achieving it.
- Helping to keep yourself, your partners, and your community healthy.
- Allowing yourself to continue to be a role model for future generations.
- Being persistent. Adopting a new habit like taking a pill everyday can be challenging at first. Additionally, some people might



be misunderstanding of the lifestyles that people who use PrEP lead, and they might disapprove PrEP. Stay strong and do not give up.

- Strengthening your support system. Talk with your friends who take PrEP and share best practices for staying adherent.
- Giving back. Share your experience with others. You may be able to help someone else and become a support system to others who might be considering PrEP as a prevention method.



5. Additional Actions that Tribes or Tribal Organizations Can Take to Integrate PrEP

STEPS TO STARTING A PREP PROGRAM IN A COMMUNITY

In addition to the points that have been mentioned, cultural aspects of integration of PrEP must be considered: cultural knowledge, awareness and perception of PrEP.

Discuss:

1. As previously stated, if staff members, especially any new staff, are interested in becoming an *HIV Prevention Certified Provider*,²⁹ there are various training events available. Various federal divisions offer trainings and supportive courses (both online and in-person) on PrEP.

If the Tribe or organization has a relationship with IHS, CDC, SAMHSA, or HRSA, they should inquire with their project officer or Tribal liaison on how to access these resources and how to obtain certification.

2. When it comes to integrating new services into existing ones, some technical assistance might be needed. Organizations could receive this capacity building assistance from IHS³⁰ and the organizations funded to deliver this type of assistance. As stated by IHS, “the IHS National HIV/AIDS Program (HIV/AIDS) coordinates and promotes HIV/AIDS prevention and treatment activities specific to Indians

29 <https://www.brainshark.com/brainshark/public/ssreg/register.asp?SSReg=1&UserId=8658209&CompanyId=2227843>

30 <https://www.ihs.gov/hiv aids/>



as part of a comprehensive public health approach. In addition to providing medical care to eligible beneficiaries, the IHS also serves as a public health system. The goals of the HIV/AIDS Program are to prevent further spread of HIV and improve health outcomes for those already living with HIV and AIDS.” These goals are achieved through the following:

- identifying new approaches to implement effective prevention interventions;
- developing HIV prevention and care standards and performance measures;
- reducing and preventing new infections by communicating public health messages on the importance of knowing personal HIV status;
- increasing routine HIV screening;
- increasing access to care and improving health outcomes for people living with HIV and AIDS;
- developing policies and procedures to sustain preventative successes including confidentiality concerns;
- utilizing media to expand access to information about testing, stigma prevention, and HIV education for health care providers and AI/AN people; and
- providing technical assistance to Indian Tribes, Tribal organizations, and urban Indian

organizations regarding these HIV/AIDS prevention and treatment programs.

3. It is important to consult with supervisors, health directors, clinical managers, or IHS project officers regarding the HIV and PrEP-specific Tribal policy recommendations and to ensure organizations align with IHS or other national guidelines.
4. It is important to note what billing and diagnostic codes to put into a patient record. The International Classification of Diseases, Tenth Revision, Clinical Modification (ICD-10-CM) coding system does not designate specific codes for PrEP or PEP related services, rather they use codes for exposure to HIV. However, the codes listed here could be options for providers to use when discussing and prescribing PrEP and PEP.
 - Z20.6 Contact with and (suspected) exposure to HIV
 - Z20.2 Contact with and (suspected) exposure to infections with a predominantly sexual mode of transmission
 - Z11.3 Encounter for screening for infections with a predominantly sexual mode of transmission
 - Z11.4 Encounter for screening for human immunodeficiency virus



- Z11.59 Encounter for screening for other viral diseases
- Z20.5 Contact with and (suspected) exposure to viral hepatitis
- Z71.7 Encounter for HIV counseling
- Z77.21 Contact with and (suspected) exposure to potentially hazardous body fluids

HOW TO RAISE AWARENESS IN THE COMMUNITY AND REDUCE STIGMA

One of the most important aspects of having conversations with individuals about PrEP is being comfortable talking about it, as well as increasing the comforts of the person so that they can talk about their own sexual behaviors, HIV, and their ability to take PrEP as prescribed. Building this trust is a pivotal action needed before integrating PrEP into current services. This relationship is best for those who already serve the community in the HIV field. Who are trusted, knowledgeable, competent, friendly, comfortable and able to work with people of varying backgrounds, experiences, and identities, and able to provide reassurance that the actions the person is taking to increase protection in their life are great steps towards their overall well-being?

Other aspects that any service provider must consider is how stigma has affected and continues to affect American Indian and Alaska Native

communities. In many situations, AI/AN people who learn that they are HIV positive are ashamed and afraid that their families and communities will find out. They may avoid seeking care, and therefore cannot access the antiretroviral drugs that would have enabled them to lead healthy, full lives.

“*There’s great stigma attached to HIV in this community and in others, it’s the biggest obstacle to effectively battling this disease.*”

“*The feeling of having no one to turn to is indescribable.*”

“*Our silence inadvertently tells them that their lives do not matter.*”

Foundationally, historical and intergenerational trauma, stemming from initial colonization, has created a domino effect of risk factors that compound existing stigma and has led to other significant barriers to addressing HIV. These include having non-Native providers serve AI/AN communities, insensitivity to current political issues, previously unseen animosity and confusion over sexual and gender identities, inaccessibility of service, lack of HIV prevention materials (including condoms), and a daunting history of infectious diseases in AI/AN communities.

Even providers and community-based organizations delivering HIV services may unknowingly support stigma by shaming certain behaviors and identities. Some sex-positive advocates might cross the line by shaming those who may not be as open about their sexuality. Sensitivity is critical to address the needs of community members who are not as knowledgeable and comfortable talking about sex, HIV, and other behaviors – whether in person, in public, and online. It is important to maintain a balance between advocacy and respect to minimize stigma felt across the entire spectrum of behaviors and identities.

The implementation of protective factors that ease anxiety, increase uptake of messaging, create community buy-in, or expedite acceptance or adoption of messages is critical. This could include the spiritual healing that comes from culture, and how it can be holistically intertwined with western medicine and other prevention activities.

Lastly, it is important to note that culture continues to change and how sensitivity in provider's approaches must change with it. For example, there has been a shift from messages emphasizing elder care to ones empowering youth to use their voices on matters of community health.

ALIGNING PREP EFFORTS WITH TRADITIONAL MEDICINE/HEALING

As a PrEP champion or prescriber, staff members must be prepared to answer critical questions that people may ask, such as, “Would PrEP interact with the traditional medicine I take?” This presents an opportunity for Western practitioners to communicate with and involve Tribal leaders, other clinicians, lay members, medicine people, and other individuals within the Tribal community that are trusted and seen as leaders, and have conversations with them about what PrEP is and how it can benefit the community and enhance the holistic healing of a person.

Dr. Iralu mentioned that for individuals who practice traditional medicine, it is important to remember that PrEP must be presented as complementary treatment followed by an invitation to the person to talk to a doctor who could reinforce this message. Again, for this, Tribes or organizations must establish a strong relationship and maintain consistent interaction with Tribal leaders, other practitioners, and lay members to ensure the person receives a consistent message regarding the benefits he or she can receive from taking PrEP as part of their holistic approach to their health.

Non-Tribal healthy systems or organizations wanting to integrate PrEP as one of the referrals services can facilitate these conversations to help everyone learn about PrEP, to assist community members in asking and answering questions, and support each other's efforts.



6. Additional Considerations

Another important consideration to keep in mind is foreseeing and addressing challenges incorporating PrEP services into current services. This includes how to integrate posters, train front line staff, communicate with prescribers, handle costs associated with PrEP promoting activities, incorporate a social media campaign on PrEP, support community members that cannot access PrEP or afford PrEP coverage, etc.

In addition to considering PrEP, there is also an approach for taking a pill after an exposure. PEP (post-exposure prophylaxis) is an option for someone who thinks they've recently been exposed to HIV during sex or through sharing needles and/or drug preparation equipment. PEP means taking antiretroviral medicines after a potential exposure to HIV to prevent becoming infected. PEP must be started within 72 hours of possible exposure to HIV. If prescribed PEP, patients will need to take it once or twice daily for 28 days. More information about PEP can be found in the following fact sheet.³¹

³¹ <https://www.cdc.gov/hiv/pdf/library/factsheets/cdc-hiv-pep101.pdf>

PEP 101

If you may have been exposed to HIV* in the last 72 hours, talk to your health care provider, an emergency room doctor, or your local health department about PEP right away. PEP can reduce your chance of becoming HIV-positive.

What Is PEP?

- PEP, or post-exposure prophylaxis, means taking medicines after you may have been exposed to HIV to prevent becoming infected.
- **PEP must be started within 72 hours (3 days) after you may have been exposed to HIV.** But the sooner you start PEP, the better. Every hour counts!
- If your health care provider prescribes PEP, you'll need to take it once or twice daily for 28 days.
- PEP is effective in preventing HIV, but not 100%. Always use condoms with sex partners and use safe injection practices.



Is PEP Right For You?

If you're HIV-negative or don't know your HIV status, and in the last **72 hours** you



- May have been exposed to HIV during sex (for example, if the condom broke),
- Shared needles, syringes, or other equipment to inject drugs, or
- Were sexually assaulted,



Talk to your health care provider, an emergency room doctor, or your local health department about PEP right away.

Can I Take A Round Of PEP Every Time I Have Sex Without A Condom?



- No. PEP should be used only in emergency situations.
- If you are at very high risk for HIV, ask your health care provider about daily medicine to prevent HIV, called pre-exposure prophylaxis (PrEP).



** People are exposed to HIV by coming into contact with certain body fluids of a person with HIV, including blood, semen, and vaginal fluids. This usually happens through vaginal or anal sex or by sharing needles.*

For more information please visit www.cdc.gov/hiv

National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention
Division of HIV/AIDS Prevention





7. Additional Resources

- What is PrEP? — A Brief Video Introduction: <https://youtu.be/GYmZwmDZGQo>
- The PrEP Locator can help find local PrEP providers: <https://npin.cdc.gov/prelocator>
- <https://www.ihs.gov/hivaids/hivaian/>
- <https://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-report-2017-vol-29.pdf>
- <https://www.cdc.gov/hiv/basics/prep.html>
- <https://www.cdc.gov/hiv/basics/whatishiv.html>
- <https://aidsinfo.nih.gov/understanding-hiv-aids/glossary/3315/non-occupational-post-exposure-prophylaxis>
- <https://www.cdc.gov/hiv/basics/pep.html>
- <https://www.cdc.gov/std/general/default.htm>
- https://www.google.com/url?q=https://www.ihs.gov/sites/telebehavioral/themes/responsive2017/display_objects/documents/slides/lgbt/lgbtnativeout.pdf&sa=D&ust=1573225817591000&usg=AFQjCNFh86dVbEq1EXhVZSs3wmQjS4G6jQ
- <https://www.cdc.gov/hiv/risk/art/index.html>
- <https://www.cdc.gov/hiv/basics/prep.html>
- <https://www.hiv.gov/hiv-basics/hiv-prevention/using-hiv-medication-to-reduce-risk/pre-exposure-prophylaxis>
- <https://www.nytimes.com/2019/10/09/us/california-hiv-drugs-prep.html>
- <https://prepfacts.org/prep/the-questions/>



