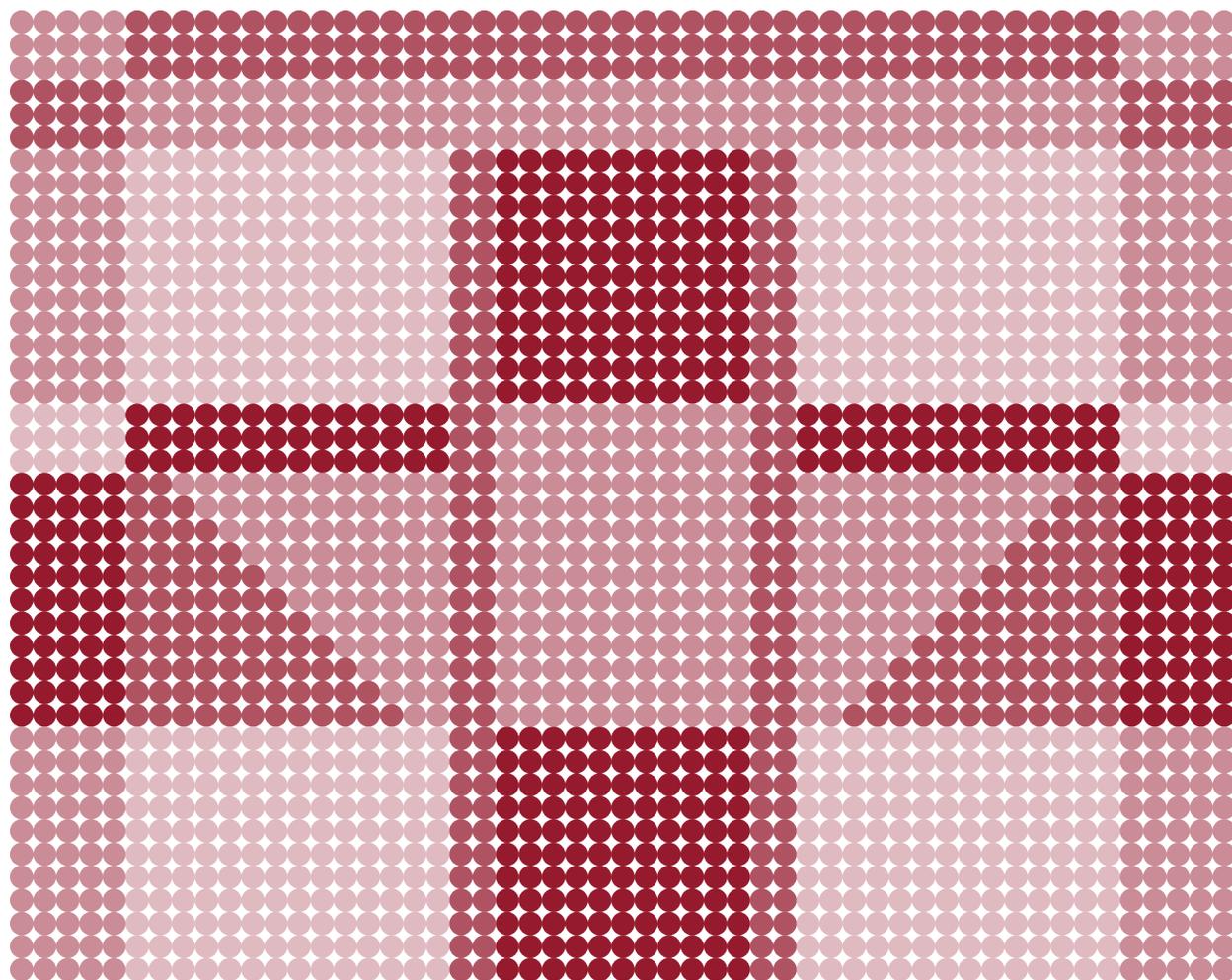# HIV Testing Toolkit

For primary care providers and clinical staff who serve American Indian and Alaska Native (AI/AN) patient populations and wish to implement HIV testing in their practice.

Urban Indian Health Institute

TABLE OF CONTENTS

INTRODUCTION

Purpose

Urban Indian Health Institute (UIHI) is developing this toolkit for primary care providers and clinical staff who serve American Indian and Alaska Native (AI/AN) patient populations and wish to implement HIV testing in their practice. For those who already implement HIV testing, this toolkit also provides quality improvement tips and resources to expand and improve their services.

When serving AI/AN populations, it's important to incorporate culturally attuned strategies that are consistent with national standards of public health. By maximizing HIV screening workflows, clinics can reduce rates of transmission and provide accessible and timely care to people who are currently living with HIV (PLWH).

HIV in AI/AN Communities: Looking at the Data

- From 2012 to 2016, HIV diagnoses increased by 34% among AI/ANs overall and 58% among AI/AN gay and bisexual men.[1]
- At the end of 2019, 20% of AI/ANs living with HIV were unaware of their status, compared to just 11% of the national population.[2]

These numbers show that—in lieu of increased incidence rates—a significant number of patients are still unaware of their status. By implementing HIV testing and strengthening existing programs, more PLWH can become aware of their status and limit community spread. However, in order to build a successful testing program, it's important to first understand and address the barriers to care that many AI/ANs experience.

Barriers to Care

In understanding why AI/ANs have higher rates of undiagnosed HIV, there must first be knowledge of the cultural, financial, and historical barriers that are experienced by AI/ANs pursuing clinical care. Practicing cultural humility will inspire more inclusive and compassionate care.

Stigma: Systemic racism, historical misinformation around HIV/AIDS, homophobic attitudes toward LGBTQ2S+ individuals, and negative perceptions around injection drug use are all examples of stigma-related barriers that affect patients seeking sexual health care. Clinics should ensure that staff are providing culturally attuned and trauma-informed care within their practice.

Historical trauma: The forced colonization of Indigenous peoples has had lasting and significant effects on AI/ANs seeking any type of medical care. Mistrust of institutions, discrimination, and prior traumatic medical experiences are all examples of how the effects of historical trauma can discourage AI/ANs from re-engaging with clinics. Acknowledging the effects of historical trauma and creating open and trusting doctor-patient relationships is an important step to addressing these barriers.

Social determinants of health (SDOH): AI/AN communities often face a lack of local and federal resources, greater health disparities, lack of access and/or transportation to clinics, higher rates of poverty, and higher rates of uninsured individuals. Many of these are a result of colonization and systemic, historical racism imposed upon AI/AN populations. Many of these inequities can be observed by looking at the current data.[3]

- In 2019, 20.3% of AI/ANs lived at the poverty level, compared to just 9.0% of non-Hispanic whites.
- In 2019, the overall unemployment rate for AI/ANs was 7.9%, compared to just 3.7% for non-Hispanic whites.
- In 2019, 14.9% of AI/ANs had no health insurance coverage, compared to just 6.3% for non-Hispanic whites.

Organizations should consider implementing programs that can address specific inequities, such as providing transportation services or financial assistance.

LANGUAGE: TALKING ABOUT HIV

The language that providers and clinical staff use can have significant and unintentional impacts on people seeking care. This effect can often be negative; however, it can also be positive and empowering. For AI/ANs who experience racism, discrimination, stigma, and trauma, adjusting the language we use can go a long way in creating a safe and welcoming medical environment.

First, it's important to acknowledge that AI/ANs report the highest levels of perceived racism in health care when compared to other racial groups.[4] Being aware of internal biases that exist within language is one tool that can help establish trust and rapport between patients and care providers.

However, it's also important to understand how language can have a positive and empowering effect on patients.

Practice providing de-stigmatizing care for your patients by assessing your everyday language. Below are a few dos and don'ts when it comes to providing care for AI/AN patients:

Do: Introduce yourself and your pronouns/preferred name, allowing patients an opportunity to provide their own.
  - LGBTQ2S+ men are disproportionately affected by HIV. Providing a safe and culturally sensitive environment for them to receive medical care is critical in reducing transmission.[5]

Don't: Never assume the pronouns or name of your patient. Misgendering and/or deadnaming a patient can be invalidating and become a deterrent for care.

Do: Apologize. Providing a sincere apology and committing to correcting a mistake after misgendering or deadnaming someone can show your patient that you value their identity.

Do: Gather resources specific to LGBTQ2S+ individuals.

Don't: Do not rely on patients alone to educate you. Do your own research to provide gender-affirming care.

Do: Take note of a patient's gender identity, sexuality, and preferred name so that other providers and clinical staff can be aware as well.

Do: Reassure patients that all conversations are private and a protected right under HIPAA.

Do: Use whole-person, people-first language. This means emphasizing a condition as something that a person has, rather than who they are. For example, use terms like "person who uses drugs" rather than stigmatizing terms like "junkie" or "druggie".

Don't: Avoid using technical language or medical jargon. Try to use plain language and neutral, clinically accurate terms.

Practicing Conversations

Below is a list of example dialogue for providers who wish to talk with patients about HIV and HIV testing in an inclusive, empowering, and destigmatizing way.

Prompts for Talking with Patients about HIV and HIV Testing

Topic	Prompt
Offering HIV testing (following the "opt-out" model)	"As part of today's visit, we will be performing a routine screening for HIV. This is something we do with all of our patients to ensure their health and safety." *(If using rapid test)* "It will be very quick, and the results will be ready before you leave here today." "The purpose of this routine screening is to ensure that we are keeping our patients healthy. In the case of a positive test, it's important to know that there are many effective treatments for HIV to both decrease transmission and help you live a healthy life." "If you do not wish to be tested, you have a right to decline this test. It will not affect the care you receive today."
Disclosing a negative test result	*Use clinical, neutral, and direct language.* "Your HIV test result is negative." *No further testing is needed. If patient may have been exposed in the last three months, recommend follow-up testing.* "Sometimes, it can take a little time for HIV to appear in a test result. Considering this, I want to ask you if you may have been exposed to HIV any time in the last three months." *(If yes)* "In order to be extra safe, I recommend that you return for testing in three months." (For Antigen tests, this timeframe may be shorter) Assess potential risk and provide options and resources. Recommend common models of HIV harm reduction. "To prevent the potential of transmission in the future, consider using condoms or water-based lubricants when having sex." "Avoiding sharing or re-using needles is one way that you can limit the potential of transmission." "I encourage you to maintain an open dialogue with your sexual partner(s) about your sexual health. Routine testing and incorporating prevention practices can help ensure that you and your partners are having safer and healthier sex." "Pre-Exposure Prophylaxis, or PrEP, is a daily pill that can prevent the spread of HIV. If you are interested, we can discuss whether this is the right option for you and your sexual health."

Prompts for Talking with Patients about HIV and HIV Testing

Topic	Prompt
Disclosing a positive test result	*Use clinical, neutral, and direct language.*
	"Your HIV test result is positive."
	Wait and allow the patient time to process and respond at their own pace before continuing. Frequently, patients report not remembering the rest of the appointment after hearing news of a positive diagnosis.
	Be attentive to the initial emotions of your patient and provide support.
	"I understand this might be a lot to process. I want to check in on how you're feeling at the moment."
	"If you need some time to think, please do not hesitate to take some space. We have plenty of time to discuss this result."
	"While this might feel overwhelming, it's important to take this one step at a time. With your permission, I can call you tomorrow and see how you're doing."
	"It's possible that you may think of questions after leaving here today. Please feel free to call me or schedule an appointment, and we can go over some of your concerns."
	Consider next steps, including emotional and mental support.
	"Is there somebody in your life who can provide some support for you during this time?"
	"Many patients find that taking some time to adjust after the initial shock can be helpful."
	"Are there any sexual partners who may need to know about your result?"
	"How might you bring up your results with your partner?"
	Clarify misconceptions and remind patients that it's possible to live a healthy life with HIV.
	"It's important to know that there are effective treatments available, and people living with HIV can live healthy and productive lives."
	"With proper medical care and attention, people living with HIV can have normal and healthy sexual relationships with HIV-negative partners."
	"Do you have any questions about HIV or HIV infection?"
	Provide referrals and explain the importance of being engaged in care.
	"There are a lot of options for people living with HIV. It's important to connect with your medical provider in order for you to receive the best care possible."
	"It's important for people living with HIV to receive regular medical follow-ups and remain engaged in care. Remaining engaged in care can help you achieve and maintain viral suppression."
	"I would like to provide you with a referral for services that can help you live with HIV. Is this something that you would be interested in?"

GUIDELINES FOR TESTING

Who Should be Tested, and How Often?

The Centers for Disease Control and Prevention (CDC) recommends that everyone between the ages of 13 and 64 get tested for HIV at least once as part of routine health care.

However, the CDC recommends yearly testing for patients who meet the following:[6]

- Are men who have sex with other men
- Have had anal or vaginal sex with someone who has HIV
- Have had more than one sex partner since their last HIV test
- Have injected drugs and shared needles, syringes, or other drug-injection equipment (e.g., cookers) with others
- Have exchanged sex for drugs or money
- Have been diagnosed with, or treated for, another STI
- Have been diagnosed with, or treated for, hepatitis or tuberculosis
- Have had sex with someone who fits any of the above criteria or someone whose sexual history they don't know

> Note: sexually active gay and bisexual men may benefit from more frequent testing (e.g., every 3 to 6 months).

Clinical Quality Measures

Electronic clinical quality measures (eCQMs) can be used to better understand the processes, experiences, and/or outcomes of patient care and treatment. As part of this, clinics can use eCQMs to identify specific patient populations and better evaluate the quality of care being provided. When it comes to HIV testing, UIHI suggests evaluating the following:

- Percentage of patients aged 13–64 who have been tested for HIV.
- Data broken down by age, socioeconomic status, sexual orientation, and gender identity.

Clinics should use this data as a baseline before implementing interventions.

Improving Screening Rates

To increase screening rates within the patient population, consider implementing some of the simple changes below that can make a big difference:

Electronic Health Record (EHR) reminders: Reminders generated in EHRs can improve screening rates by nearly 50%.[7,8] Clinics should consider programming reminders into the EHR system so patients and providers are aware of testing and can take the initiative to schedule appointments.

Sexual health assessments: Completing a thorough sexual health assessment can help providers and clinical staff assess how often a patient should be tested. When conducting a sexual health assessment, it's important to remember that sex is often a sensitive topic, and one should approach it in a way that's affirmational toward the patient.

- Use transitional statements to help switch topics rather than abruptly beginning to talk about sexual health.
- Consider statements that normalize the topic and help patients feel that others have similar issues or concerns.
- Explain why you are asking these questions, so they understand and can give proper consent.
- Use clear language—not medical jargon—so patients have a better understanding of what they are being asked.
- Consider using a range of options or scaling-type questions. This can help patients feel that their responses will be heard and not judged.
- Affirm the patient's right not to answer any questions that might make them uncomfortable. This reinforces that their autonomy and power are respected.
- Use a tone that is non-judgmental and non-shaming so that patients feel respected and open to engagement.
- Focus your questions on the Five Ps: Partners, Practices, Protection from STIs, Past history of STIs, and Pregnancy Plans and Prevention.

Prompting for residents by preceptors: Encouraging preceptors to prompt their residents to screen for HIV can have a significant effect on screening rates. In a 2017 study, screening increased from 4% to over 75% when preceptors were urging residents to screen for HIV.[9]

Provider education: Continuing provider education can be effective in increasing screening. In partnership with Cardea services, UIHI has developed a series of e-learning modules for providers and nurses who wish to receive training on topics such as culturally proficient health care, sexual health assessments, talking with patients about HIV, and more. Upon completion, participants will be eligible to receive continuing education credits. To access these learning modules, visit https://cardeaservices.org/resource/hiv-care-and-sexual-health-assessment-for-american-indian-and-alaska-native-patients.

Collecting HIV testing data in the EHR: Even if the correct data is collected, it can often be misplaced or recorded in the wrong spot. Consider checking in with staff and colleagues to ensure that EHR data is being recorded correctly and all screenings are accounted for.

- Racial misclassification is a leading factor in the underrepresentation of Native communities in public health surveillance systems. Limited or misclassified race data can prevent the understanding of the true health disparities among AI/AN and other populations. Ensure that all race data is collected and recorded properly.

CLINIC POLICIES AND WORKFLOW

To ensure a patient is connected to HIV care and remains engaged in their care plan, it's important to establish clear organizational communication channels and department expectations. This includes creating clinical workflows that outline HIV testing, prevention, and treatment strategies within a medical center that moves a patient through the HIV care continuum. According to the CDC, for every 100 AI/AN patients diagnosed with HIV, 57 were retained in care and 63 were virally suppressed.[10]

Considerations for Urban Indian Organizations

For programs serving Native people, attention should be given to specific areas of the HIV testing program.

Funding and Staffing: Applying for grant funding may assist with the hiring and training of staff members to manage and conduct HIV rapid tests. Ensure that appropriate staff are available to follow up with patients and provide referrals.

Retention in Care: Focusing on patient follow-up and integrative care within workflows is important in identifying patients at high risk of HIV or PLWH. Design workflows to ensure that patients are not lost between appointments or referrals.

Referrals: Improving internal and/or external referrals to mental health and social services can ensure that patients are engaged in HIV testing, prevention, and treatment. Create systems to identify patients who would benefit from referrals and appropriate follow-up.

Local Regulations: Ensure that workflows follow clinical guidelines, HIPAA regulations, and local reporting requirements for HIV testing.

Workflow Stakeholders
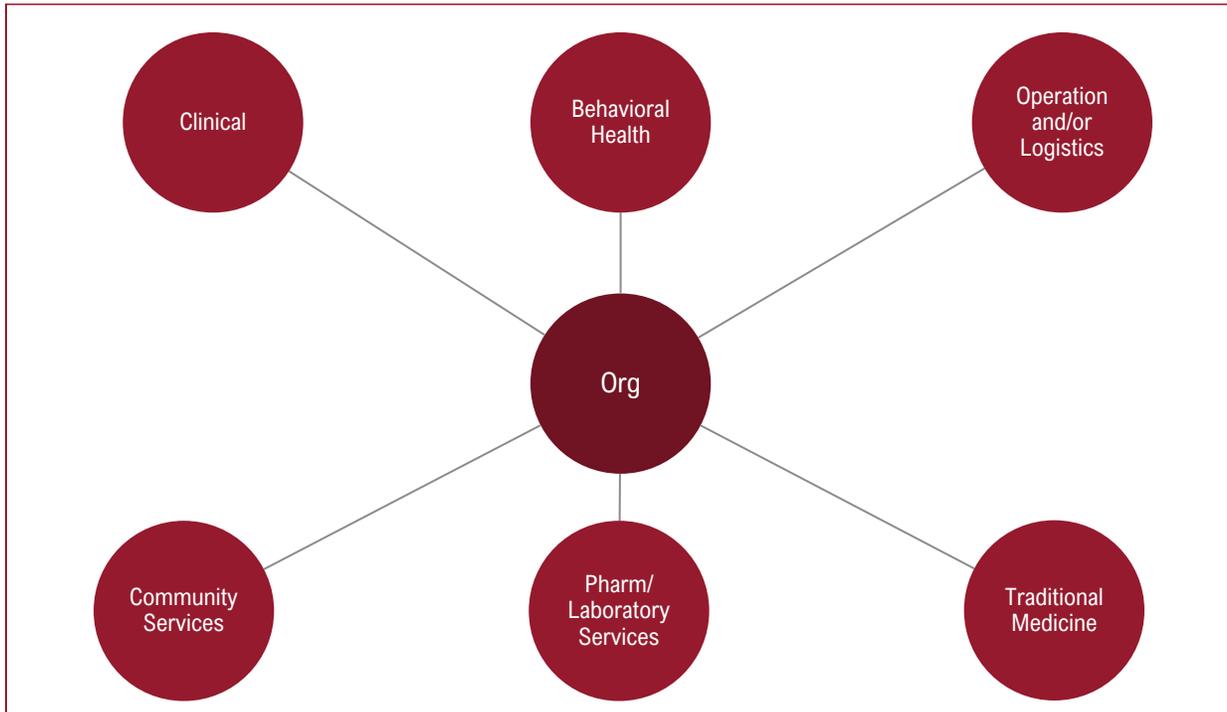
Decisions for Testing

Organizations have several options to integrate HIV testing into their services depending on their clinical capacity, funding, and priorities. If an organization already provides HIV testing services, it may expand its offerings to establish opt-out testing. If an organization does not have clinical or laboratory support, it may offer referrals and connections to care.

Please see additional resources linked below for more information on what options may be available.

Test Type: Point-of-care vs. Confirmatory

Test Setting: In-clinic vs. self-testing

Test Identification: Automated vs. physician-led screening

Example Workflows

- HIV Testing Script for Clinicians: https://www.cdc.gov/hiv/pdf/testing/cdc_hiv_scripts-rapid_hiv_testing_for_individuals.pdf
- Flowchart Example: https://cdn.sanity.io/images/0vv8moc6/patientcare/3e6d3545349342bde0d65ff397be752dd5e15ddf-520x521.gif
- Visual Clinic Flow Example: https://www.researchgate.net/figure/HIV-patient-flow-map-for-standard-of-care-and-fast-track-queues-Times-are-reported-in_fig3_325096862

TESTING FOLLOW-UP

Overview

Staying in the care continuum is one of the most important aspects of U=U and TasP. Only four out of five PLWH know they have HIV, and even less know they have HIV and stay in care. Using effective workflows and follow-up measures can help mitigate this challenge.

Strategies for Increased Retention in Care

Strategy	Level of Effort	Explanation
Train staff members in HIV Testing with Follow-up Included	5/5	Ensure staff have the appropriate training on ways to ensure patients receive appropriate, culturally attuned follow-up during and after their HIV testing session. Resource: UIHI Cardea Module Series
Scheduling for Confirmatory Testing after Point-of-Care Testing	3/5	Before an individual receives the point-of-care test, take a minute to schedule the patient's confirmatory test. If your clinic provides confirmatory testing, use your scheduling system to make an appointment on the spot. If you must refer the patient out to an external clinic, provide the referral and recommended follow-up timeline, and identify an individual or automated system to call, or message the patient for reminders. NOTE: If you offer confirmatory testing but the patient would have to wait an extended period of time for an appointment, you may consider an external referral for the patient to receive a quick answer. The World Health Organization recommends starting anti-retroviral therapy on the same day that the patient is diagnosed.[11]
Give Guidance on HIV Prevention and Tools for Prevention	4/5	Ensure patients understand how they can remain HIV negative. Assign a care navigator to schedule regular testing and prevention counseling Recommend a PrEP plan Train providers and/or pharmacy staff to build PrEP capacity Provide harm reduction resources (e.g., guide to syringe service programs in your area) Distribute free condoms[12] Consider a process for couples' HIV counseling[13] Resource: Regional AIDS Education and Training Centers (AETCs)
Determine Adherence Goals for HIV Plans	3/5	Discuss with patients their adherence to prevention or treatment plans and consistency in taking prescribed medication. Adjust if necessary: Intensity of clinical follow-up Shortening follow-up interval Recruiting more healthcare team members Involving family and friends in plans[14]

Strategy	Level of Effort	Explanation
External Specialty Care Referrals	2/5	Identify one or more clinic locations to refer patients diagnosed with HIV to for comprehensive services.
		Things to keep in mind when referring out:
		Ensure your organization maintains reliable and continuous communication between agencies
		Determine steps for follow-up with patient and the other agency
		Consider processes to make the appointment for the patient, and remove additional barriers to accessing care at the referred to agency
		Ensure the patient will be culturally safe at the referred to agency
Provide Educational Materials	1/5	Provide hard copies or direct any individuals receiving an HIV test to educational materials on HIV, HCV, and other STIs. A variety of informational materials for American Indian and Alaska Native communities can be found at https://www.uihi.org/projects/urban-indian-hiv-and-aids/.
Refer to Additional Health and Human Services	3/5	Ensure patients have the culturally attuned and trauma-informed services they need to stay in care. This may include:
		Medical/pharmaceutical payments
		Transportation
		Housing
		Meals
		Behavioral health care opportunities
		Substance use programs
		Gender-based violence services
		Community/culture programming
		Resources: Create a resource map—like this COVID-19 map from the Seattle Indian Health Board—or identify one provided by your region or county.
Continue Regular Screening and Testing	4/5	Assign a care navigator or develop a system in your EHR to schedule a follow-up appointment for testing in six months to one year depending on an individual patient's risk level. At these follow-up appointments, check in to see if a patient's sexual health has changed in any way.
Recommend Partner Testing	1/5	When providing HIV Counseling, inform the patient about different HIV and other STI testing options for their partners, as well.
		Resource: CDC's Partner Services Information Site
Patient-guided Follow-up	1/5	Let the patient decide how you will be following up—via phone, e-mail, text message, fax, home visit, etc. as available. Be mindful of patient confidentiality in all follow-ups. Ask for patient's preferred names and pronouns, and use them in all follow-up messages.[14]

With 0 being no effort required and 5 being significant time, leadership commitment, and staff involvement.

COMMUNITY OUTREACH

To limit the spread of HIV and increase awareness of status, community buy-in is necessary. One way to coordinate efforts among local populations is through outreach. Offering HIV rapid testing and other resources at pow wows, fairs, homeless shelters, and more, is one way to expand access to services and promote knowledge of status.

One study that implemented these methods in community settings saw a 60% acceptance rate for HIV rapid testing, with a total of 23,900 individuals tested.[15] Of those tested, 267 were newly diagnosed with HIV, with the highest rates among those at bathhouses, social service organizations, and needle-exchange programs. The study provides a valuable example of how employing rapid testing in community settings is an effective way of reaching people at high risk of HIV infection.

Strategies for Community Engagement

Focus outreach to locations with individuals who are at high-risk of HIV. This can be needle exchanges, social services, homeless shelters, community clinics, treatment facilities, bars, and more.

Prioritize privacy for those being tested. Set up privacy screens, tents, private rooms, or mobile testing units. Ensure each patient that their results will be confidential.

Organize appropriate training for those who deliver tests. For more information, visit the CDC's website on HIV Testing in Nonclinical Settings. This includes a three-day, virtual CDC training for those who wish to provide testing.

Consider incentivizing testing. To encourage passersby to get tested, consider offering incentives in the form of gift cards, coupons, food, etc. For those who might require follow-up, consider offering transportation options or subsidies.

Set up confirmatory testing and post-test counseling. For those who test positive, gather specimens for confirmatory testing. Have an employee on site who can conduct post-test counseling and offer follow-up appointments and referrals.

CLOSING/RESOURCES

Below is a list of resources that UIHI recommends when implementing, expanding, and/or improving HIV testing services within your clinic.

- Addressing Racial Misclassification
- Best Practices in HIV Reporting and Data Collection in AI/AN Communities
- Responding to Emerging HIV Clusters
- HIV Care and Sexual Health Assessment for AI/ANs
- HIV Care and Sexual Health Assessment Provider Toolkit https://www.uihi.org/download/hiv-care-and-sexual-assessment-for-american-indian-and-alaska-native-patients-provider-toolkit/?wpdmdl=19014&refresh=62a2235192e401654793041
- Trauma-informed Language for Treating People Who Use Drugs
- CDC HIV Testing
- HIV.gov HIV Testing
- IHS HIV Testing

REFERENCES

1. HIV/AIDS statistics. *IHS*. Accessed June 7, 2022. https://www.ihs.gov/hivaids/stats/

2. HIV in the United States by race/ethnicity. *CDC*. Published April 14, 2022. Accessed June 7, 2022. https://www.cdc.gov/hiv/group/racialethnic/other-races/index.html

3. American Indian/Alaska Native. *HHS/OMH*. Accessed June 7, 2022. https://www.minorityhealth.hhs.gov/omh/browse.aspx?lvl=3&lvlid=62

4. Johansson P, Jacobsen C, Buchwald D. Perceived discrimination in health care among American Indians/Alaska natives. *Ethn Dis*. 2006;16(4):766-771.

5. HIV and gay and bisexual men. CDC. Published September 16, 2021. Accessed June 7, 2022. https://www.cdc.gov/hiv/group/msm/index.html

6. HIV screening and testing. *CDC*. Published January 21, 2020. Accessed June 7, 2022. https://www.cdc.gov/hiv/guidelines/testing.html

7. Kershaw C, Taylor JL, Horowitz G, et al. Use of an electronic medical record reminder improves HIV screening. *BMC Health Serv Res*. 2018;18(1):14. doi:10.1186/s12913-017-2824-9

8. Electronic Health Record assists in routine HIV screening. *JAMA*. 2014;312(8):781. doi:10.1001/jama.2014.9985

9. Doering T, Mohamed S, Hollar L, Pugh Z. Quality improvement for HIV screening in a primary care resident clinic. *J Community Hosp Intern Med Perspect*. 2017;7(2):79-81. doi:10.1080/20009666.2017.1313491

10. HIV in the United States by race/ethnicity: viral suppression. *CDC*. Published May 31, 2022. Accessed June 7, 2022. https://www.cdc.gov/hiv/group/racialethnic/other-races/viral-suppression.html

11. *Recommendation for rapid initiation of art*. *WHO*. 2017. Accessed June 21, 2022. https://www.ncbi.nlm.nih.gov/books/NBK475972/

12. Prevention. *CDC*. Published March 23, 2022. Accessed June 21, 2022. https://www.cdc.gov/hiv/basics/prevention.html

13. Guidance on couples HIV testing and counselling including antiretroviral therapy for treatment and prevention in Serodiscordant couples: recommendations for a public health approach. *WHO*. 2012. Accessed June 21, 2022. https://www.ncbi.nlm.nih.gov/books/NBK138280/

14. Iacob SA, Iacob DG, Jugulete G. Improving the adherence to antiretroviral therapy, a difficult but essential task for a successful HIV treatment—clinical points of view and practical considerations. *Front Pharmacol*. 2017;8:831. doi:10.3389/fphar.2017.00831

15. Bowles KE, Clark HA, Tai E, et al. Implementing rapid HIV testing in outreach and community settings: results from an advancing HIV prevention demonstration project conducted in seven U.S. cities. *Public Health Rep*. 2008;123(Suppl 3):78-85.