



REPORT

Improving HIV Surveillance Among American Indians And Alaska Natives in the United States

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Executive Summary

In proposed action steps to address the National HIV/AIDS Strategy goal of reducing new HIV infections, the Federal Implementation Plan for the Strategy specifically encourages improved surveillance to better characterize HIV among American Indians and Alaska Natives (AI/AN). The Implementation Plan calls for the Centers for Disease Control and Prevention (CDC) to provide state health departments that have high concentrations of AI/AN populations with recommendations on effective HIV surveillance activities. To develop these recommendations, CDC followed a two-step process. First, an assessment was conducted from July through September 2011, including a literature review and a series of discussions with representatives of AI/AN public health agencies and organizations and the Indian Health Service (IHS), as well as several state health departments. Second, current AI/AN-related HIV surveillance practices were assessed through focus group and key informant discussions with HIV surveillance staff in six states and three cities within them that have separately funded HIV surveillance programs and have the largest populations or proportions of AI/AN persons (Alaska, Arizona, California, New Mexico, Oklahoma, Texas and Los Angeles, San Francisco and Houston). Five areas for improvement of HIV surveillance among AI/AN were identified from the literature and discussions with staff in the jurisdictions: 1) ascertainment of HIV infection; 2) reporting of diagnoses to surveillance; 3) identification of the race/ethnicity of reported cases; 4) effectiveness of data presentation in surveillance reports; and 5) dissemination of AI/AN surveillance data.

The literature review, focus groups and key informant interviews also identified action steps to improve HIV surveillance among AI/AN including: 1) routine or periodic linkage of HIV surveillance data to other databases (such as tribal membership rolls or the IHS National Patient Registration System (NPRS) to correct race/ethnicity misidentification; 2) combining several years of data and reporting AI/AN-specific data rather than subsuming these data under an “other” race/ethnicity category; 3) working through a Tribal Liaison,

Indian Health Board (IHB), or Tribal Epidemiology Center (TEC) to identify data needs of AI/AN Tribes, communities, and non-governmental organizations; 4) accommodating these data needs through analysis of surveillance data by zip code or county to approximate the boundaries of tribal lands or communities; and 5) establishing formal and informal agreements, including provisions for data sharing to ensure that data reach those empowered to use them for public health action in AI/AN communities.

The applicability and feasibility of these suggested improvements were discussed with the HIV surveillance coordinators in states and cities that participated in this assessment. Some approaches to addressing needed improvements in surveillance were found to be applicable to or feasible in some jurisdictions and not others. Based on the findings of the assessment, five standard practices should be implemented:

1. Promote protocols for routine, opt-out HIV testing in accordance with CDC recommendations;
2. Identify providers serving AI/AN patients, including social service providers, community based organizations (CBOs), and laboratories conducting HIV testing of AI/AN persons, and follow up to encourage the reporting of all positive HIV tests to local or state health departments;
3. Present, in surveillance reports, cases with documented single AI/AN race (AI/AN only without Hispanic ethnicity), and separately, present AI/AN cases with and without Hispanic ethnicity;
4. Analyze and present summary information on AI/AN annually, separately from other races/ethnicities, if numbers of cases are sufficiently large, according to data release guidelines; otherwise, combine data across years;
5. Send AI/AN HIV surveillance reports and summary information directly to AI/AN Tribes, agencies and organizations that have expressed a need for this information.

Furthermore, CDC identified 15 recommended practices supporting effective HIV surveillance among AI/AN:

1. Expand testing and encourage testing outreach to AI/AN persons through AI/AN Tribes, agencies, and organizations;
2. Utilize available culturally appropriate “know your status” and HIV awareness materials directed toward AI/AN;
3. Present AI/AN HIV surveillance information to AI/AN Tribes, agencies, and organizations, and emphasize the importance of complete reporting, including reporting of risk factors, for improved usefulness of the data;
4. Promote HIV case reporting by facilities serving AI/AN persons, including establishment of agreements between state health departments and tribal and community-based organizations that provide HIV testing; conduct special studies to evaluate completeness of reporting.
5. Develop formal data sharing agreements between state health departments, IHS/Tribal/Urban health facilities, and tribal organizations, in accordance with current data security and confidentiality guidelines, to strengthen collaboration on surveillance;
6. Identify ways to encourage more accurate documentation of race/ethnicity in medical records;
7. Utilize data sources with self-reported or family-reported race, such as Ryan White program data, to improve the completeness and accuracy of race/ethnicity in surveillance data;
8. Contact providers for race/ethnicity information when the case report indicates non-AI/AN race and diagnosis has occurred in an IHS-funded, AI/AN-focused CBO, or tribally operated facility, or there is other information suggestive of AI/AN race;
9. Partner with Tribes, IHBs, TECs and IHS to identify and correct misidentification of race/ethnicity by periodically linking HIV surveillance data with tribal membership rolls or the IHS patient registration system;
10. Work with AI/AN Tribes, IHBs, and TECs as well as non-governmental AI/AN-serving organizations to identify HIV surveillance information needed and address these needs;
11. Produce and disseminate AI/AN-focused HIV reports or fact sheets using local HIV surveillance data;
12. Partner with Tribes, IHBs, AI/AN-focused CBOs, and TECs to conduct within-jurisdiction regional analyses that cover areas of high concentration of AI/AN people;
13. Collaborate with other states and Tribes, IHBs, AI/AN-focused CBOs, and TECs to combine data for broader regional analyses of AI/AN HIV surveillance data
14. Proactively identify and offer assistance to AI/AN Tribes, agencies, and organizations that have information needs and/or technical assistance or capacity building assistance related to interpreting and using HIV surveillance data;
15. Promote the use of AI/AN HIV surveillance data through presentations to HIV prevention planning groups, health care providers that serve AI/AN, and AI/AN-focused prevention programs.

Introduction

The three primary goals of the *National HIV/AIDS Strategy* (NHAS) are: 1) reducing the number of people who become infected with HIV, 2) increasing access to care and optimizing health outcomes for people living with HIV, and 3) reducing HIV-related

health disparities.¹ To achieve these goals, the Federal Implementation Plan for the Strategy specifically encourages improved surveillance to better characterize HIV among smaller populations such as American Indians and Alaska Natives (AI/AN) and calls for the Centers for Disease Control and Prevention (CDC) to provide state health departments that have high concentrations of AI/AN populations with recommendations on effective HIV surveillance activities.² This report provides these recommendations and describes the activities that led to their development.

Background

According to the 2010 U.S. Census, a total of 5.2 million individuals reported their race as AI/AN, representing 1.7% of the U.S. population, including 2.9 million reporting AI/AN race alone and 2.3 million reporting AI/AN in combination with one or more other races.³ Between 2000 and 2010, the AI/AN population grew by 1.1 million, a 26.7% increase; the overall U.S. population grew by 9.7% in comparison. Hispanic or Latino ethnicity was reported by 1.2 million AI/AN (23%). In 2010, the median age of AI/AN persons was 29 years as compared with 37 years for the U.S. population as a whole. More than one-fifth (22%) of AI/AN persons lived in American Indian areas or Alaska Native Village Statistical Areas. Forty percent of AI/AN adults and adolescents lived in rural areas in the United States in 2008 compared with 16% of other race/ethnicity groups combined.⁴ The population of AI/AN, including those of more than one race, is projected to grow to 8.6 million and comprise 2% of the U.S. population by 2050.³

The AI/AN population is heterogeneous, including 566 federally recognized tribes with sovereign status as domestic, dependent nations and with different languages, cultures, and tribal governance structures, as well as varied social, historical and economic conditions that affect social determinants of health.^{3,5} Some states recognize tribes that are not federally recognized.⁶

In addition to health care services received from the private and public providers who serve other Americans, AI/AN persons from federally recognized Tribes are eligible for care under the federally funded Indian Health Service (IHS). Health care services were provided to 2 million AI/AN persons in 2012 by programs funded by the IHS; some of these programs are operated by IHS and some are tribally operated or operated as urban Indian health centers, and these programs are collectively referred to as I/T/U facilities.^{5,7} State laws regarding reporting of new HIV diagnoses apply equally to providers and laboratories serving I/T/U facilities as to other providers licensed in states. Although it is in the best interest of a facility to report HIV cases (e.g., to document numbers of HIV cases for funding purposes), facilities may not be legally compelled to do so and their voluntary HIV case reporting practices may vary.

HIV Surveillance

Although the annual numbers of new diagnoses of HIV infection among AI/AN remain relatively low compared with other race/ethnicity groups, AI/AN diagnosis rates per 100,000 population are higher than those for whites and Asians.⁸ Moreover, AI/AN have a shorter survival time after diagnosis. Among AI/AN diagnosed during 1996-2005, 47.2% received an AIDS diagnosis within 3 years of initial HIV diagnosis (an indicator of late diagnosis), a higher percentage than for whites (42.6%) and black/African Americans (46.1%) and a lower percentage than for Hispanics/Latinos (48.4%) and Asians (50.4%).⁹ AI/AN diagnosed during 2002-2006 were less likely to survive 12, 24 or 36 months after HIV diagnosis compared with any other single race or ethnic group.⁸

The effectiveness of the HIV case surveillance system for AI/AN depends on a number of factors: HIV test-seeking behaviors of individuals and testing practices of providers; AI/AN access to HIV testing; case reporting to state systems by providers, laboratories and facilities; correct identification of AI/AN race; appropriate data analysis methods; and dissemination

of surveillance information useful for prevention and community health-care planning. A greater estimated percentage of AI/AN infected with HIV were undiagnosed by the end of 2008, compared with whites, blacks/African Americans, and Hispanics/Latinos, which may reflect lower HIV testing access, uptake, or coverage among AI/AN at risk for HIV.¹⁰ One survey of urban AI/AN at higher risk for HIV found that 44% of those who reported high-risk behaviors perceived themselves to have low or no risk for HIV, even though most had received HIV prevention messages.¹¹ These findings suggest that culturally appropriate educational initiatives to encourage accurate perception of HIV risk may help to improve uptake of HIV testing among AI/AN. Risk factor information was missing for 26% of AI/AN diagnosed in 2010 (unadjusted) and approximately 73% of diagnoses of HIV infections among AI/AN males could be attributed to male-to-male sexual contact (adjusted for missing risk factor).⁸ Improved risk factor ascertainment by clinicians submitting case reports can contribute important information to guide prevention and outreach efforts.

Concerns have been raised about whether all diagnoses of HIV among AI/AN persons are reported as required by state laws.⁷ In surveys of AI/AN and state health agencies, respondents raised the possibilities that lack of trust, particularly between tribal authorities and state or local governments, and a lack of mutually agreed-upon arrangements for reporting cases across state-tribal jurisdictional boundaries may be barriers to reporting cases to surveillance.^{12,13} Underreporting could be occurring in some geographic areas, although to date there have been no published studies evaluating completeness of reporting.⁷ However, there is evidence that racial misidentification may cause considerable underestimation of AI/AN HIV cases.¹⁴⁻¹⁷ One study of racial misidentification in HIV/AIDS reporting systems in five states and one urban county found that 4% to 55% of AI/AN persons with reported diagnoses across these jurisdictions had been misidentified as not being of AI/AN race in HIV surveillance case records.¹⁵

Different methods of defining AI/AN and reporting HIV diagnoses by race/ethnicity groups can affect the availability of information on HIV among AI/AN for policy, prevention and health care planning for affected AI/AN communities. In 2002, the Office of Management and Budget (OMB) recommended that diverse small groups like AI/AN not be combined with other groups in race/ethnicity categories because these combined data offer minimal useful information for public health programs.¹⁴ The effect of HIV on AI/AN communities may be underestimated by race/ethnicity reporting conventions for HIV surveillance in which individuals of any race with Hispanic ethnicity are counted in the “Hispanic, all races” group, and individuals without Hispanic ethnicity but who report more than one race are classified in the “Multiple Race” group. These reporting conventions have a greater effect on HIV surveillance among AI/AN than other races because of the higher proportion of mixed race/ethnicity reported by persons identifying themselves as AI/AN (44% in the 2010 Census, compared with 3% among all races).³ Also, published surveillance data analyzed by county or state may not be meaningful for AI/AN Tribes and communities with boundaries that do not coincide with county or state borders.¹³

HIV Surveillance Systems

[HIV Case Surveillance](#)

Within the first few years of the HIV epidemic in the United States, all U.S. states, the District of Columbia, and the U.S. dependent areas were reporting diagnoses of acquired immunodeficiency syndrome (AIDS) to CDC using a standardized system.¹⁰ In 1994, CDC expanded the national surveillance system to include diagnoses of both HIV infection and AIDS, and 25 states with confidential name-based HIV infection reporting began submitting case reports to CDC. Over time, additional areas implemented confidential name-based HIV surveillance and all states, the District of Columbia and 5 dependent areas had implemented such surveillance by April 2008. The latest adjusted

estimates of diagnoses of HIV infection published in the National HIV Surveillance Report include 46 states and 5 dependent areas that have had confidential name-based HIV reporting since January 2007, including all of the states with large AI/AN populations. The estimates are limited to these 51 jurisdictions to allow for statistical adjustments for reporting delays.⁸ Beginning in 2012, data from all states are expected to be included in national reports. All cases are reported to CDC without identifying information. National HIV case surveillance also includes the collection of supplemental data in states funded for HIV Incidence Surveillance (HIS), Variant, Atypical and Resistance HIV Surveillance (VARHS), and Geocoding and Linkage Activities with HIV Data (GLAHD).

For most data analyses, national HIV surveillance reports follow conventions that place AI/AN persons who are also Hispanic into the Hispanic/Latino category and persons reported as both AI/AN and another reported race into the Multiple Races category.⁸

[Medical Monitoring Project](#)

The Medical Monitoring Project (MMP) is a national, population-based surveillance system that collects information on clinical outcomes and behaviors of HIV-infected persons receiving care in the United States.¹⁸ Collection of data from interviews with HIV-infected patients provides information on current levels of behaviors that may facilitate HIV transmission; patients' access to, use of, and barriers to HIV-related secondary prevention services; utilization of HIV-related medical services; and adherence to drug regimens. Through abstraction of medical records, MMP also provides information on clinical conditions that occur in HIV-infected persons as a result of their disease or the medications they take, receipt of HIV care and support services, and the quality of these services. Less than 1% of MMP respondents in the 2007 MMP data collection cycle were AI/AN.¹⁸

[National HIV Behavioral Surveillance System](#)

The National HIV Behavioral Surveillance System (NHBS) is CDC's most comprehensive system for conducting behavioral surveillance among persons at highest risk for HIV infection in the United States.¹⁹ The overall strategy for NHBS involves conducting rotating annual cycles of surveillance in three different populations at high risk for HIV: men who have sex with men (MSM), injection drug users (IDUs) and heterosexuals at increased risk for HIV. Surveillance is conducted in 20 cities in the United States which have high AIDS prevalence. NHBS collects detailed information on HIV risk behaviors, HIV testing and use of prevention services. AI/AN represented <1% of respondents from the first and second NHBS data collection cycles among MSM and the first cycle among IDUs.²⁰⁻²²

Methods

CDC conducted a literature review to: 1) identify gaps in and barriers to surveillance of HIV infection among AI/AN; 2) explore suggestions for improving surveillance; 3) describe what is being done to enhance HIV surveillance among AI/AN in the United States and Canada; 4) examine practices to enhance surveillance for other health conditions among AI/AN; and 5) identify models for sharing surveillance data with AI/AN tribal organizations and communities. We selected six states and three cities within these states that have separately funded HIV surveillance programs; these areas have the largest populations or proportions of AI/AN persons in the United States (Alaska, Arizona, California, New Mexico, Oklahoma, Texas, Los Angeles, San Francisco and Houston). HIV surveillance staff in the selected jurisdictions were contacted to assess, through group discussions, the current AI/AN-related HIV surveillance practices and the feasibility of suggested improvements. The assessment was focused on the needs for improvement identified through literature review and by the representatives of AI/AN agencies. These activities led to our proposed recommendations for improving HIV surveillance among AI/AN. Through the literature

review and a series of group dialogs, conference calls, and key informant discussions with representatives of AI/AN public health agencies and organizations, AI/AN-focused community based organizations (CBOs), and IHS, we identified needed improvements in HIV surveillance among AI/AN and action steps to effect these improvements.

Summary of Key Findings on Improving Surveillance of HIV Infection among AI/AN Persons

CDC identified five areas for improvement related to surveillance of HIV infection among AI/AN from the literature review, group discussions and key informant interviews. These include improving: 1) ascertainment of HIV infection; 2) reporting of diagnosed cases to health departments; 3) identification of the race/ethnicity on case reports; 4) effectiveness of data presentation in surveillance reports (particularly the practice of subsuming AI/AN reported cases into an “other” race/ethnicity category and into geographic areas that do not reflect concentrations of AI/AN people or I/T/U service areas; and 5) dissemination of AI/AN surveillance data so that those data reach those in a position to use the data for decision making about HIV prevention and care.

The literature review, group discussions and key informant interviews also identified action steps to improve surveillance among AI/AN, including: 1) routine or periodic linkage of HIV surveillance data to other databases (such as tribal membership rolls or the IHS NPRS) to correct race/ethnicity misidentification; 2) combining several years of data and reporting AI/AN-specific data rather than subsuming these data under an “other” race/ethnicity category; 3) working through a Tribal Liaison, Indian Health Board (IHB), or Tribal Epidemiology Center (TEC) to identify data needs; 4) accommodating data needs of AI/AN Tribes and organizations through analysis of data by zip code or county to approximate the boundaries of tribal lands or communities; and 5) establishing formal or informal data-sharing agreements to ensure that data reach those

empowered to use them for public health action in AI/AN communities.

The six state surveillance programs interviewed for this report vary widely with respect to the geographic distribution patterns of AI/AN persons within their jurisdictions, such as the existence of geographic concentrations of AI/AN individuals, the size of communities with a high proportion of AI/AN persons and whether there are separate, tribal jurisdictions (federally or state-recognized) contiguous with state boundaries.

Findings from the literature review, group discussions, and key informant interviews with representatives of AI/AN agencies and IHS indicated that the geographic concentration of AI/AN in communities and the presence of government-funded health services may determine where HIV diagnoses are made and the quality of the information in case reports from facilities providing diagnoses. For example, IHS, tribally operated, and CBO facilities performing HIV testing may report AI/AN race more accurately than do facilities that provide health care services to more general populations, regardless of AI/AN identity. In contrast, states with geographically dispersed AI/AN populations receiving testing at facilities that are neither funded by IHS nor tribally operated have fewer opportunities to develop a systematic means to correct racial misidentification of AI/AN.

Surveillance also depends on strong case-reporting relationships between providers from health-care facilities and nonclinical HIV testing facilities where HIV diagnoses are made and state and local health departments. The strength of these relationships may vary across facilities serving AI/AN persons within a surveillance jurisdiction and across jurisdictions. In addition, if HIV testing is performed on tribal lands adjacent to more than one state, jurisdictional issues may hinder reporting of diagnoses. Because of differences in the distribution of AI/AN communities, access points for HIV testing, case reporting and

case-reporting relationships, and the overall numbers of reported AI/AN HIV cases across jurisdictions, some approaches to improving surveillance may be more applicable or feasible for some jurisdictions than others. We therefore focused group discussions with HIV surveillance staff in the six selected jurisdictions on identifying approaches that were both applicable and feasible in their jurisdictions. Key findings from these discussions are presented below.

1. Case Ascertainment —Timely and accurate ascertainment (case identification) is essential to effective public health surveillance, including HIV surveillance. Ascertainment of HIV infection in AI/AN populations may be improved through general expansion of HIV testing or through testing that is specifically targeted toward reaching AI/AN, especially those at highest risk, for example male-bodied Two-Spirit persons or MSM. The IHS National HIV/AIDS Administrative Work Plan 2008-2011 recommends routine HIV testing.^{23,24} IHS Women’s Health Guidelines issued in 2005 included a performance standard for opt-out prenatal screening to increase the number of AI/AN persons who know their status and to decrease mother-to-child transmission.^{24,25} A recent collaboration between CDC and IHS has resulted in new IHS guidelines for sexually transmitted disease (STD) screening, including HIV testing.²⁶ However, our key informant interviews suggested that these guidelines have not yet been widely implemented. Because reporting of cases to surveillance is conditional on diagnosis of infection, some informants suggested that HIV testing programs and surveillance units of state health departments collaborate more closely to increase provider awareness of HIV testing guidelines, particularly in rural settings where there are challenges associated with testing and reporting cases and where many AI/AN reside.

In addition to routine HIV testing in clinics and by providers who serve AI/AN patients, the literature

supports offering testing in non-clinical venues (e.g., community-based organizations, schools, community awareness events) and promoting opt-out testing at other sites (e.g., correctional facilities, substance abuse treatment centers).²⁷ Both the published literature and key informants mentioned the reluctance of many AI/AN to be tested in their local communities because of confidentiality concerns and stigma. Specific considerations related to confidentiality may apply to opt-out testing, especially in facilities located on reservations and in small communities. Culturally appropriate social marketing is needed to make HIV testing more routine and acceptable.

2. Case Reporting – State and city HIV surveillance coordinators interviewed noted that new cases, including diagnoses among AI/AN persons, were usually reported by laboratories, not health-care providers. At least one state reported that small laboratories that serve I/T/U facilities did not report all positive tests. Although clinicians and laboratories serving I/T/U facilities are subject to the same reporting laws as other laboratories and clinicians licensed in a state, some HIV surveillance coordinators who participated in our assessment were uncertain whether all cases diagnosed in I/T/U sites are being reported. Some key informants noted that confusion about case reporting responsibilities may contribute to underreporting when a person is diagnosed on tribal lands or in a state other than his or her state of residence. Others suggested special studies for HIV case finding as well as data sharing with IHS, tribal health organizations, and CBOs to improve reporting of AI/AN HIV diagnoses.

3. Identification of AI/AN Race – The literature review yielded examples of linking HIV surveillance and other public health surveillance databases with other data sources that may have more accurate race/ethnicity information and have been used to correct misidentified race/ethnicity.²⁸⁻²⁹ Some of the

key informants reported conducting such linkages and finding them useful, but they also noted that these linkages are labor intensive and that the capacity to perform them routinely is limited. Some key informants suggested assuming AI/AN race when a case with unspecified AI/AN race/ethnicity is reported from an IHS-funded facility. Others pointed out that assuming all cases reported from IHS-funded facilities are of AI/AN race may be problematic because Commissioned Corps officers and non-AI/AN family members may be allowed access to IHS-funded care. Some key informants emphasized that the AI/AN race of a relatively large number of AI/AN persons with Hispanic or Latino ethnicity is often missed in analyses of surveillance data. By convention, most analyses assign all persons with Hispanic/Latino ethnicity, including AI/AN persons, as Hispanic/Latino (i.e., individuals who are both AI/AN and Hispanic/Latino are not counted in the AI/AN group). Several jurisdictions suggested that surveillance data be analyzed to reflect all AI/AN (with and without Hispanic/Latino ethnicity) as well as in the conventional way.

4. Presentation of AI/AN HIV Surveillance

Data – Surveillance staff noted challenges in displaying data for small numbers of AI/AN in annual and supplemental surveillance reports. Several informants mentioned concerns that AI/AN cases are displayed in the ‘other’ race/ethnicity category, rendering information specific to AI/AN inaccessible. Suggestions included creating special reports on AI/AN using merged data from several years, so that data on small populations can be presented without violating confidentiality and data release standards. Several jurisdictions independently suggested that reporting all AI/AN, including those with Hispanic/Latino ethnicity, might help to address this problem.

5. Dissemination of AI/AN HIV Surveillance

Information – HIV surveillance staff and the

literature review suggested that HIV reporting could be strengthened by better collaboration with tribal health departments and organizations through mutual recognition of each other’s functions, needs, and vested interests in the data, and through data sharing.^{30,31} Some states have formal data-sharing agreements or memoranda of agreement (MOA) with Tribes, such as the agreement between the Arizona Department of Public Health and the Gila River Indian Community.³² Other state health departments have informal data-sharing agreements with TECs, IHS, IHBs, and Urban Indian Health Programs. The few formal data sharing agreements described were usually created for one-time studies or activities. Some data-sharing agreements currently in effect that pertain to sexually transmitted diseases could be expanded to include HIV. Programs choosing to share data should do so in accordance with current data security and confidentiality guidelines.³³

Furthermore, the HIV Surveillance Coordinators and other informants reported that data sharing with tribal organizations, community planning groups and health-care providers is valuable for prevention and care planning. Some tribal leaders are not aware that HIV is a problem in their jurisdiction. The importance of sharing surveillance reports and summary information with Tribes and tribal leaders was mentioned by some HIV surveillance staff, but these activities are apparently not being conducted by all states with adjacent federal and state-recognized AI/AN tribal jurisdictions.

Although some state health departments provide reports upon request to Tribes and groups concerned with AI/AN health, and some include tribal leaders and health care providers in routine mailings of their standard HIV Surveillance Report, most do not routinely provide specific AI/AN-focused reports to HIV prevention community

planning groups. Some surveillance staff reported having a Tribal Liaison in their state, but that this liaison has not been asked to work on health-related issues like HIV surveillance. Other surveillance staff did not know if their health department did or did not have a Tribal Liaison but agreed a liaison could be useful for better communication with Tribes.

Whereas some cities had data-sharing agreements with urban AI/AN clinics, others were unaware of urban clinics that operate in their jurisdictions. Because approximately 50% of AI/AN HIV cases are diagnosed in metropolitan areas, the potential for improving surveillance by working with IHS-funded or other urban Indian health programs may be underappreciated. Misidentification of race/ethnicity may be more common among AI/AN persons living in urban areas vs. rural areas (or on reservations)¹⁵, and working with the urban Indian health programs may be a way to address this problem.

The legal environment surrounding the exchange of identifiable health data between state health departments and TECs for lawful public health activities conducted by the TECs has been explored by Hodge et al., in a recent report to the Council of State and Territorial Epidemiologists. The authors concluded that “legal barriers that thwart these data-sharing practices should be assessed within each jurisdiction and remedied, where possible, through legal interpretations or tools discussed in this report, or approved in each jurisdiction.”³⁴

Recommendations

According to the Federal Implementation Plan of the NHAS, CDC is tasked with making recommendations to state health departments for effective AI/AN HIV surveillance activities. Recognizing that some approaches may be applicable in some jurisdictions but not others, and approaches that are applicable may not always be feasible, we propose recommendations for improvements that should be standard practices of

surveillance programs. We also propose recommended practices that expand on these basic improvements, to be implemented where possible.

The purpose of public health surveillance is to serve as a foundation for action to improve health, but the use of surveillance data may be limited if surveillance is ineffective. For surveillance data to be effective, HIV infection must be diagnosed. Even when surveillance is effective, its use may be limited. Therefore, the recommendations below address both identification of infection and use of surveillance data, and are directed toward health department HIV testing and prevention programs as well as surveillance programs. To fulfill the purpose of HIV surveillance among AI/AN, state health departments must work continuously to develop and improve relationships with Tribal governments, IHS, and non-governmental AI/AN-serving HIV prevention programs and care services, and implement these recommendations with their input and collaboration.

1. Improve ascertainment of infection (case identification)

Standard practice:

- Promote protocols for routine, opt-out HIV testing in accordance with CDC’s Revised Recommendations for HIV Testing of Adults, Adolescents and Pregnant Women in Health-Care Settings.³⁵

Recommended practice:

- Expand testing and encourage testing outreach to AI/AN persons through AI/AN Tribes, agencies, and organizations.
- Utilize available culturally appropriate “know your status” and HIV awareness materials directed toward AI/AN.

Information on testing programs and National Native HIV/AIDS Awareness Day toolkits are available from sources such as:

- » Commitment to Action for 7th-Generation Awareness & Education (CA7AE) HIV/AIDS Prevention Project: <http://www.happ.colostate.edu/nad.html>;
- » National Native American AIDS Prevention Center: <http://www.nnaapc.org/resources/promotehivtesting.htm>.
- » Northern Plains Tribal Epidemiology Center: <http://gptchb.org/nptec/stdhiv aids.php?page=3>
- » Northwest Portland Area Indian Health Board: http://www.npaihb.org/epicenter/project/project_red_talon/

2. Improve reporting of diagnoses

Standard practice:

- Identify providers serving AI/AN patients, including social service providers, community based organizations (CBOs), and laboratories conducting HIV testing of AI/AN persons, and follow up to encourage the reporting of all positive HIV tests to local or state health departments.

Recommended practice:

- Present AI/AN HIV surveillance information to AI/AN Tribes, agencies, and organizations, and emphasize the importance of complete reporting, including reporting of risk factors, for improved usefulness of the data.
- Promote HIV case reporting by facilities serving AI/AN persons, including establishment of agreements between state health departments and tribal and community-based organizations that perform HIV testing. Conduct special studies to evaluate completeness of reporting.
- Develop formal data sharing agreements between state health departments, IHS/Tribal/Urban health facilities (I/T/U) and tribal organizations, in accordance with current data security and

confidentiality guidelines, to strengthen collaboration on surveillance.

3. Reduce racial/ethnic misidentification

Standard practice:

- Present, in surveillance reports, cases with documented single AI/AN race (AI/AN only without Hispanic ethnicity), and, separately, present AI/AN cases with and without Hispanic ethnicity.

Recommended practice:

- Identify ways to encourage more accurate documentation of race/ethnicity in medical records.
- Utilize data sources with self-reported or family-reported race, such as Ryan White program data, to improve the completeness and accuracy of race/ethnicity in surveillance data.
- Contact providers for race/ethnicity information when the case report indicates non-AI/AN race and diagnosis has occurred in an IHS-funded, AI/AN-focused CBO, or tribally operated facility, or there is other information suggestive of AI/AN race.
- Partner with Tribes, IHBs, TECs and IHS to identify and correct misidentification of race/ethnicity by periodically linking HIV surveillance data with tribal membership rolls or the IHS patient registration system.

4. Improve analysis and presentation of data

Standard practice:

- Analyze and present summary information on HIV among AI/AN annually, separately from other races/ethnicities, if numbers of AI/AN cases are deemed sufficiently large, according to data release guidelines.^{33,36} Otherwise, combine data across years.

Recommended practice:

- Work with AI/AN Tribes, IHBs, and TECs as well as non-governmental AI/AN-serving organizations to identify HIV surveillance information needed and address these needs.
- Produce and disseminate AI/AN-focused HIV reports or fact sheets using local HIV surveillance data.
- Partner with Tribes, IHBs, AI/AN-focused CBOs and TECs to conduct within-jurisdiction regional analyses that cover areas of high concentration of AI/AN people.
- Collaborate with other states and Tribes, IHBs, AI/AN-focused CBOs, and TECs, to combine data for broader regional analyses of AI/AN HIV surveillance data.

5. Improve dissemination of data

Standard practice:

- Send AI/AN HIV surveillance reports and summary information directly to AI/AN Tribes, agencies, and organizations that have expressed a need for this information.

Recommended practice:

- Proactively identify and offer assistance to AI/AN Tribes, agencies, and organizations that have information needs and/or need technical assistance or capacity building assistance related to interpreting and using HIV surveillance data.
- Promote the use of AI/AN HIV surveillance data through presentations to HIV prevention planning groups, health care providers that serve AI/AN, and AI/AN-focused prevention programs

Contributors

CDC staff involved in preparing this report: Jeanne Bertolli, Behavioral and Clinical Surveillance Branch, Division of HIV/AIDS Prevention; Jane Kelly, HIV

Incidence and Case Surveillance Branch, Division of HIV/AIDS Prevention; Frances Walker, HIV Incidence and Case Surveillance Branch; Division of HIV/AIDS Prevention.

Other CDC staff consulted: Melanie Taylor, Epidemiology and Surveillance Branch, Division of STD Prevention Assignee to Maricopa County Department of Public Health and IHS National STD Program; Scott Tulloch, Office of Health Equity, Division of STD Prevention Assignee to IHS National STD Program.

External experts:

Alaska Native Epidemiology Center: Ellen Provost, Director; *Alaska Native Tribal Health Consortium HIV Program:* Beth Saltonstall, Medical Director; *California Rural Indian Health Board:* Richelle Harklerode, Epidemiologist; *Colorado Dept. of Public Health & Environment:* Ralph Wilmoth, STI/HIV Section Chief; Anita Watkins, Regional Staff Epidemiologist, Tri-County Health Department; *Colorado State University, CA7AE: HIV/AIDS Prevention Project:* Pamela Jumper-Thurman; *Florida Department of Health:* Kate Goodin, Senior Epidemiologist, Bureau of Epidemiology; *Great Plains Tribal Chairmen's Health Board:* Jennifer Irving, CSTE Intern; John Dunham, HIV Program, Tribal Epidemiology Center; *Indian Health Board of Nevada:* Angel Stachnik, Epidemiologist; *Indian Health Service:* Rear Admiral Scott Giberson, National HIV/AIDS Program, Principal Consultant; Lisa Neel, Program Analyst, National HIV/AIDS Program; Brigg Reilly, HIV Surveillance Coordinator, National HIV/AIDS Program; Jennifer Giroux, Medical Epidemiologist, IHS Liaison to the Tribal Epidemiology Center, Great Plains Tribal Chairmen's Health Board; Jonathan Iralu, Infectious Disease Consultant, Navajo Area; Karen Bitsoie, IHS Phoenix Indian Medical Center; Thomas Weiser, Medical Epidemiologist, Portland Area Indian Health Service assigned to Northwest Portland Area Indian Health Board; *Indigenous Peoples Task Force:* Sharon Day; *Michigan Department of Community Health:* Danielle Smith; *Minnesota Department of Health:*

Allison LaPointe, HIV Surveillance Coordinator, HIV/STD Epidemiology and Surveillance Unit; *Montana Department of Public Health & Human Services*: Steve Helgerson, State Medical Officer; *Native American AIDS Project, San Francisco*: Gayle Burns, Prevention Case Manager; *Navajo AIDS Network*: Melvin Harrison; *Navajo Tribal Epidemiology Center*: Dornell Pete, Director; David Foley, Navajo Division of Health, Epidemiologist, Navajo Division of Health; *Nevada State Health Division*: Chad Williams, Tribal Liaison; *North Dakota Department of Health*: Tracy Miller, State Epidemiologist, Krissie L. Guerard, HIV/TB Program Manager, Craig Steffens, HIV Surveillance Coordinator; *NorthEast Two-Spirit Society*: Harlan Pruden; *Northwest Portland Area Indian Health Board*: Megan Hoopes, NW Tribal Registry Director; Jessica Leston, Project Red Talon; *Oklahoma State Department of Health*: Kristy Bradley, State Epidemiologist. *Oregon State Public Health Division*: Richard Leman, Medical Epidemiologist; *Red Circle Project, AIDS Project of Los Angeles*: Elton Naswood; *Rocky Mountain Tribal Epi Center*: Karen Chin, Epidemiologist; Helen Tesfai, Epidemiologist; *South Dakota Department of Health*: Christine Olson, HIV Surveillance Coordinator and Ryan White CARE/ADAP Program Manager; *Seattle Indian Health Board, Urban Indian Health Institute*: Crystal Tetrick, Associate Director; Elizabeth Knaster, Project Coordinator; *Utah Department of Health*: Matthew Mietchen, Utah HIV Program, Surveillance Coordinator; *Washington State Department of Health*: Marcia Goldoft, Medical Epidemiologist; *Wisconsin Department of Health Services, HIV/AIDS Program*: Wendy Schell, HIV/AIDS Surveillance Coordinator, Mari Gasiorowicz, Epidemiologist; Marisa Stanley, Epidemiologist; and Anneke Mohr, Population Health Fellow.

State health department staff interviewed:

Alaska Department of Health & Social Services: Melissa Boyette, HIV Surveillance Coordinator; *Arizona Department of Health Services*: Rick DeStephens, HIV Program Manager; Mersija Hadzihanovic, HIV

Coordinator; Kerry Kenney, Public Health Advisor for STD Program; Cameron Lewis, Adult Hepatitis Coordinator/Manager; Judy Norton, AIDS Director; Penelope Riley, HIV Incidence Surveillance Epidemiologist; Jana Schleff Distefano, Epidemiologist; Julia Skinner, Capacity Building, Epidemiologist; Jennifer Williams Warrington, HIV Incidence Coordinator; *California Department of Health*: Stephen Starr, Chief, HIV Surveillance Section; Karen Mark, Interim Chief, Office of AIDS; *Los Angeles County Health Department*: Juli-Ann Carlos, Epidemiologist; Douglas Frye, Director of HIV Epidemiology and HIV Surveillance Coordinator; Virginia Hu, Supervising Epidemiologist; Zhijuan Sheng, Epidemiologist; *New Mexico Department of Health*: Terry Bryant, HIV & Hepatitis Epidemiology Program Manager; Kelly Gallagher, HIV Epidemiologist; Chad Smelser, Medical Epidemiologist; *Oklahoma State Department of Health*: Kristy Bradley, State Epidemiologist; *Oklahoma State Department of Health, Division of Surveillance and Care Delivery*: Terrainia Harris, Manager of Surveillance and Analysis; Amber Rose, eHARS Manager; and Sam Nimo, HIV Epidemiologist; *San Francisco Department of Public Health*: Maree Kay Parisi, HIV Surveillance Program Director; Tony Buckman, HIV Incidence Program Field Coordinator; *Texas Department of State Health Services, TB/HIV/STD Epidemiology and Surveillance Branch*: Sharon Melville, Branch Manager; Rebecca Filipowicz, Group Manager; Miranda Fanning, Data Reporting Manager; Jennifer Chase, Epidemiologist; Casey Russell, Epidemiologist; *Houston Department of Health and Human Services*: Karen Chronister, Epidemiologist Supervisor, HIV/STD Surveillance Program.

[*Assistance from the Council of State and Territorial Epidemiologists*](#): Michael Landen, Chairman, Tribal Epidemiology Subcommittee; Annie Tran, Associate Research Analyst; Lauren Rosenberg, Associate Research Analyst; and Ellyn Marder, Epidemiology Program Intern.

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