HIV Perceptions and Testing History of American Indians (AI) residing in one Northwest Tribal Community

Introduction:

The ***American Indian and Alaska Native HIV Testing Survey*** (AI/AN HITS) was a CDC-funded project whose goal was to conduct an anonymous cross-sectional survey of self-reported HIV testing history. The specific aims of the study were: 1) to determine reasons for delaying or avoiding testing, and 2) to assess risk behaviors among high-risk Native Americans residing on reservations in OR, WA, and ID. Formative research interviews with tribal American Indians and Alaska Natives (AI/AN) were conducted to help illustrate knowledge and identify issues important to the community. With the approval of two NW Tribes, the AI/AN HITS survey was administered to approximately 174 American Indian and Alaska Native participants residing on reservations in Oregon and Washington.

Background:

Across the United States, many of the risk factors that contribute to the transmission of HIV and other sexually transmitted diseases are prevalent in American Indian and Alaska Native (AI/AN) communities.

High Background Prevalence of Sexually Transmitted Diseases (STD). Rates of several sexually transmitted diseases are high among American Indians and Alaska Natives. In 2004, American Indians were nearly five times more likely than whites to have chlamydia, four times more likely to have gonorrhea, and twice as likely to have syphilis. Following this trend, 11% of sexually active 15- to 30-year-old women screened at clinics in two IHS service areas tested positive for Chlamydia in 2003. When compared by ethnicity, American Indians and Alaska Natives had the second-highest gonorrhea rate in 2004 (117.7 per 100,000 population, representing a 14.8% increase since 2003), followed by Hispanics (71.3 per 100,000), whites (33.3 per 100,000), and Asians/Pacific Islanders (21.4 per 100,000). In addition, rates of primary and secondary syphilis among AI/ANs increased 14.3% in 2004, decreasing among men from 50 to 42 cases, but increasing among Native women from 19 cases to 35. When compared by ethnicity, AI/AN men and women both had the third highest HIV/AIDS rate in 2004.

The aforementioned data suggests that HIV rates could potentially explode—especially if AI/AN populations falsely perceive that their HIV/AIDS risk is low, or worse, if they do not think about their HIV risk at all. Contributing to this concern, having an STD can increase one's chance of acquiring or transmitting HIV through sexual exposure by 2 - 5 times.

Insufficient Access to Healthcare. Access to high-quality healthcare is essential for early detection, treatment, and counseling for sexually transmitted diseases. Unfortunately, the Indian Healthcare System is significantly under-funded and over- burdened with need. An investigation by the Government Accountability Office in September 2005 concluded, "American Indians often do not have adequate access to healthcare." Transportation, long wait times, few specialists, and rural geography further contribute to poor access.

Clinic-Based Policies. According to an STD capacity assessment administered by Project Red Talon in 2005, only 60% of respondents reported the presence of comprehensive STD screening and treatment protocols in their NW Tribal clinic. Because many STDs are asymptomatic, comprehensive clinic-based policies are critical to identifying cases and reducing partner-to-partner transmission.

Substance Abuse. Numerous studies have documented the association between drug and alcohol use and sexually transmitted diseases. Illicit substances, including alcohol, inhalants, and methamphetamines, can reduce inhibitions and drastically alter sexual behavior in high-risk sexual networks, leading to further STD transmission. Based on combined data from SAMHSA's 1999-2001 National Household Survey on Drug Abuse, AI/ANs were more likely than Blacks or Asians to have engaged in binge or heavy drinking in the past 30 days, and in 2001, had the highest rate of past year dependence/abuse of illicit drugs or alcohol of any other group. Particularly concerning for our young people, studies targeting those admitted to treatment also reveal that AI/ANs are more likely to initiate substance use at age 14 or younger (46% vs. 32%), when compared with other racial or ethnic groups.

Sexuality and Social Norms. Early sexual debut, multiple sex partners, and infrequent condom use also puts American Indians and Alaska Natives at heightened risk for STDs, HIV, and teen pregnancy. According to a 2001 Youth Risk Behavior Survey (YRBS), which involved a nationally-representative sample of 8,500 BIA high school students, youth attending BIA-funded schools were more likely to have had sex than the national sample. Slightly more than half (52.3%) of Native American female high school students reported having had sex, compared to 42.9% of all female high school students, and 65.5% Native American male students reported having had sex, compared to the 48.5% of all male high school students. While teen pregnancy rates for Native youth are not available from national data sets (due to a lack of available abortion data), in 2002 the birth rate for Native American 15- to 19- year-olds was 53.8 per 1,000, much higher than the national rate of 43.0 per 1,000.

Increasing their risk for STDs and HIV, female Native American students also reported less condom use at last sex than the total student population (45.0% vs. 51.3%). Among males, however, condom use at last sex is equally likely among Native American students and the general high school male population (64.8% vs. 65.1%). Overall, 55.9% of the sexually experienced BIA students reported using a condom at last sex, and only 8.3% of AI/AN students report using birth control pills at that time, compared to 18.2% of high school students nationally.

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Methods:

Survey Design. The *HIV Testing Survey* (HITS) was developed by the Centers for Disease Control and Prevention for use by state and county health departments to facilitate local HIV surveillance activities. The survey was designed to elicit information from high-risk adults regarding: 1) their willingness to obtain HIV testing; 2) perceived obstacles to HIV testing; and 3) knowledge of HIV testing and reporting laws and policies.

In 2001, the Northwest Portland Area Indian Health Board (NPAIHB) and Oregon Health & Science University (OHSU) collaborated on a survey project to collect data on HIV knowledge, attitudes, and behavior among urban American Indians and Alaska Natives living in Portland, Oregon. To make the HITS survey more appropriate for Native populations, urban and tribal community members helped modify the original survey.

The AI/AN HITS was modified from the original HITS by: 1) tailoring HIV perception questions toward individuals with less knowledge of HIV/AIDS; 2) adding questions about American Indian susceptibility to HIV/AIDS; 3) adding questions assessing attitudes about HIV services at American Indian health facilities; 4) adding questions on migration between urban communities and reservations; and 5) adding a section on exposure to trauma and violence.

The 2001 AI/AN HITS project enrolled and interviewed a sample of urban AI/ANs to determine the prevalence of HIV risk behaviors among adult males and females, and assess their knowledge, attitudes, and behaviors regarding HIV testing and transmission. Following this project, it was unknown, however, whether reservation-based AI/ANs would differ from urban AI/ANs in their knowledge, attitudes, and behaviors related to HIV.

On November 29th, 2001, the Portland Area Indian Health Service's IRB approved the continuation of the AI/AN HITS project in two rural Northwest Tribes.

Sampling Process. The AI/AN HITS project used a respondent-driven sampling technique to help assure that the sample population was representative of the tribal communities from which they were collected. High-risk individuals served as "seeds" to start the sampling process. These individuals were identified during the formative research process. Attempts were made to recruit men who have sex with men (MSM), intravenous drug users (IDU) and heterosexuals engaging in high-risk sex (HET) as "seeds."

After completing the AI/AN HITS survey, interviewers read a "network recruitment script" asking individuals to recruit members of their social network. Participants were each given 5 fliers to distribute to friends and acquaintances. The fliers included a number to call if the friend wanted to participate in the survey. Friends could then call in to schedule interviews, and were screened for eligibility in the same manner as seeds. Participants were not asked to give the names or contact information for their friends or family at any point.

Fliers were color-coded according to "recruitment waves." When calling to schedule an interview, individuals were asked to describe the color of the flier and bring the flier with them. This process allowed the Principal Investigator to track recruitment patterns in each community.

Screeners. A screening script was used for each tribe participating in AI/AN HITS. The screening script was used to ensure that participants were: a) American Indian or Alaska Native; b) 18 years of age or older; and c) living in the "surrounding" region (assessed appropriately for each community). At Tribe #1, the script included questions about student and military status, as those criteria were used locally to determine residency for tribal services.

Interviews. Survey responses were collected by trained interviewers during face-to-face interview sessions. To ensure data quality, interviewers were trained to review each questionnaire before the respondent left, so that any missed questions and/or mistakes in skip patterns could be corrected immediately. Completed forms were returned to NPAIHB on a weekly basis, and were reviewed by the Principal Investigator.

Sample Size. Optimal sample sizes were calculated using population figures for each participating tribe. The population was estimated using the number of active users of the Tribe's health service unit. These figures included enrolled tribal members and members of other federally recognized tribes residing within reservation boundaries.

Site	Population	Sample Size
Tribe #1	3,048	150
Tribe #2	5,000	150

Data Analysis. The data collected from tribal respondents were compiled and analyzed by staff from the Northwest Portland Area Indian Health Board. Basic descriptive statistics (e.g., frequency distributions, means, etc.) were generated in SPSS to support data analysis.

HIV risk group definitions, based on self-reported HIV status and behaviors used in the American Indian/Alaska Native HIV testing survey, 2001

Risk Group	Criteria: (One or more reported behavior(s) per respondent; Respondents categorized based on most risky behavior)
HIV positive	Tested positive for HIV
High-risk	Injection drug use[i] with known or suspected non-sterile needle Body piercing[i] with known or suspected non-sterile needle Vaginal or anal sex with 2 or more partners of the same or opposite sex in past year without ever using condoms.
Potential high-risk	Injection drug use[i], but report using new/sterile needles Vaginal or anal sex with 2 or more partners of the same or opposite sex in past year with inconsistent condom use Binge drinking[iii] in past year Other non-injection drug use[iii] in the past year
Lower risk	Do not meet any of the above criteria

** Lifetime or current behavior*
[i] Inconsistent condom use defined as any response but "always" to condom use questions.
+ Six or more drinks in one sitting
@ Includes amphetamines (meth, speed, uppers, crystal, crank, ice), crack, cocaine (smoked or snorted).

Results:

Selected Demographics of Respondents (n=122)	n	%
Gender		
Male	50	41.0
Female	72	59.0
Age		
18-24	28	23.0
25-34	26	21.3
35-44	35	28.7
45+	33	27.0
Race and ethnicity		
American Indian only	94	77.0
At least one additional race	28	23.0
Educational Attainment		
Did not complete high school	37	30.3
High school diploma or equivalent	50	41.0
More than high school	34	27.9
Employment Status		
Employed	55	45.1
Unemployed	66	54.1

*Refusals not displayed but included in denominators.

One hundred and twenty-two American Indians and Alaska Natives participated in the AI/AN HITS survey in Tribe #2. Nearly 60% of respondents were female and 40% were male, representing a broad distribution of ages, educational backgrounds, and current employment statuses.

Thirty-six percent reported they were engaging in some type of high-risk behavior, and 27% "never think about getting HIV." Nearly 37% said they believed that the risk of contracting HIV/AIDS was higher for American Indians than for the general population, but only twenty percent reported that their own chances of getting infected were moderate to high. Over half (58%) reported that they had been tested for HIV at least once in their lifetime; of those, 31% had tested in the past year. Twenty-nine percent reported that "many friends have gotten an HIV test." Many said they would be comfortable getting an HIV test at a tribal, urban Indian, or county health care facility (75%, 82% and 77%, respectively). In addition, 85% indicated that they would list their ethnic background as American Indian or Alaska Native on the form if they were to get an HIV test.

Over two thirds (69%) of respondents knew an American Indian/Alaska Native (AI/AN) who had been diagnosed with HIV, and about one third (34%) knew an AI/AN who had died of AIDS.

Respondents who agreed or strongly agreed with the following statements (n=122)	n	%
If you have HIV but feel well, medical care can help you live longer and stay healthier	98	80.3
Sometimes you do things where you might get HIV such as not using condoms or not cleaning needles	79	64.8
Many of your friends have gotten the HIV test	34	27.9
You never think about getting HIV	33	27.0
You are less careful about being safe with sex or drugs than you were 5 years ago because there are better treatments for HIV now	25	20.5
By taking the new HIV drug therapies people who are HIV positive decrease the chances that they will infect their partner with HIV	25	20.5
You would be comfortable dating someone who is infected with HIV	21	17.2
Sometimes you do things where you might get HIV because HIV is a gay man's disease	8	6.6
Sometimes you do things where you might get HIV because HIV is a white man's disease	3	2.5
You would be comfortable going to a Tribal health center for an HIV test	92	75.4
You would be comfortable going to an urban Indian health center for an HIV test	100	82.0
You would be comfortable going to a county health center for an HIV test	94	77.0
If you were to get an HIV test, you would list your ethnic background as American Indian or Alaska Native on the form	104	85.2
Do you think that the risk of contracting HIV for AI/AN is …		
… higher than the general population	45	36.9
… lower than the general population	15	12.3
… same as the general population	58	47.5
Know of any AI/AN living with HIV/AIDS	84	68.9
Know of any AI/AN who died from HIV/AIDS	42	34.4

The perceived and actual risk of getting infected with HIV was assessed using self-reported behaviors (including injection drug use, sexual activity, binge drinking, body piercings, and non-injection drug use), and questions gauging their perception of risk. Of those who engaged in high-risk behaviors, nearly 20% believed that they were indeed at high risk of acquiring HIV. Of concern, however, 60% of those that engaged in high-risk behaviors thought that they were at low risk, and 8% believed that they were at no-risk at all. Of those who reported potentially high-risk behaviors, only 6% and 14% respectively believed that they were at high- and moderate-risk for acquiring HIV, and a troubling 80% thought that they were at low- or no-risk of acquiring HIV, despite their potentially high-risk behaviors.

Perceived vs. Actual* risk of getting infected with HIV				
What are your chances of getting infected with HIV?	High-risk	Potential high-risk	Lower risk	Total
High	5 (20.8)	4 (6.2)	0 (0.0)	9 (7.4)
Medium	3 (12.5)	9 (13.8)	4 (12.1)	16 (13.1)
Low	14 (58.3)	26 (40.0)	12 (36.4)	52 (42.6)
None	2 (8.3)	26 (40.0)	17 (51.5)	45 (36.9)
Total	24 (100.0)	65 (100.0)	33 (100.0)	122 (100.0)

*Based on self-reported risk behaviors

Abstract:

Objectives: **To examine the HIV perceptions and testing history among members of two tribal communities in the Northwest US.**

Methods: **Focus groups modified the national HIV Testing Survey (HITS) to address issues unique to American Indians (AI) living in tribal communities. Modifications included gearing HIV perception questions toward individuals with less knowledge of HIV/AIDS, and adding questions about AI susceptibility to HIV/AIDS and attitudes regarding services at AI health facilities.**

Results: **There were 174 respondents to the survey. Thirty-six percent reported they were engaging in some type of high-risk behavior, and 32% "never think about getting HIV." Thirty-two percent said they believed that the risk of contracting HIV/AIDS was higher for AI than for the general population, but only seventeen percent reported that their own chances of getting infected were moderate to high. Over half (58%) reported that they had been tested for HIV at least once in their lifetime; of those, 31% had tested in the past year. Twenty-nine percent reported that "many friends have gotten an HIV test." Many said they would be comfortable getting an HIV test at a tribal, urban Indian, or county health care facility (75%, 80% and 78%, respectively). In addition, two thirds (66%) of respondents knew an American Indian/Alaska Native (AI/AN) who had been diagnosed with HIV, and about one third (35%) knew an AI/AN who had died of AIDS.**

Conclusions: **Like other populations, AI should be encouraged to ascertain their HIV status, particularly if engaged in high-risk behavior. Surprisingly, a similar majority of respondents reported that they would feel comfortable testing at tribal, urban Indian, or county sites, which suggests that this service can be provided any of those facilities with comparable success.**

Conclusions:

Like other populations, American Indians and Alaska Natives should be encouraged to ascertain their HIV status, particularly if engaged in high-risk behavior. Surprisingly, a majority of respondents reported that they would feel comfortable testing at tribal, urban Indian, or county clinics, which suggests that HIV testing services can be provided at any of these facilities with comparable success. Nearly 60% of respondents from this particular tribe reported that they had been tested for HIV at least once in their lifetime, and of those, 31% had been tested in the past year. The vast majority indicated that they would list their ethnic background as American Indian or Alaska Native on the form if they were to get an HIV test, and about a third of respondents reported having "many friends that have gotten an HIV test," suggesting that the stigma that surrounds HIV testing may be in decline in future years.

On the whole, members of Tribe #2 were fairly well educated about the importance of medical care for those infected with HIV, and false stereotypes that exist portraying HIV as a "gay man's disease" or a "white man's disease." Nearly 85% of respondents believed that the risk of contracting HIV for American Indians and Alaska Natives was either higher than or the same as the general population; only 12% believed that their risk was lower than the general population.

Despite this knowledge, survey results indicate that members of this Northwest tribe could benefit from education focused on the factors that contribute to and reduce the transmission of HIV. Significant discrepancies were found between the perceived and actual risk of acquiring HIV among those who participated in high-risk and potentially high-risk behaviors. Nearly 68% of those who were engaged in high-risk behaviors (including injection drug use with known or suspected non-sterile needles, body piercings with known or suspected non-sterile needles, vaginal or anal sex with 2 or more partners of the same or opposite sex in past year without ever using condoms, or having given or received money or drugs for sex in the past year) thought that they were at low- or no-risk of getting an HIV infection. Similarly, of those who reported potentially high-risk behaviors (including injection drug use using new/sterile needles, vaginal or anal sex with 2 or more partners of the same or opposite sex in past year with inconsistent condom use, binge drinking in the past year, and other non-injection drug use in the past year), 80% believed that they were at low- or no-risk of acquiring HIV, despite their potentially high-risk behaviors. Such findings suggest that education and outreach is needed to increase community knowledge about HIV risk factors, and promote the adoption of risk reduction strategies.

The results from the AI/AN HITS survey will be used by participating tribes to assist community planning and priority setting, and will facilitate the development and implementation of programs that encourage appropriate HIV testing and risk reduction.