



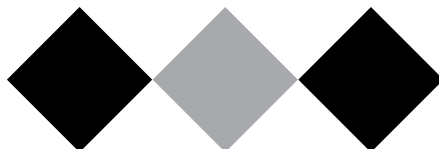
**A Way to Wellness:  
Locating and Understanding Native-Specific HIV Data**

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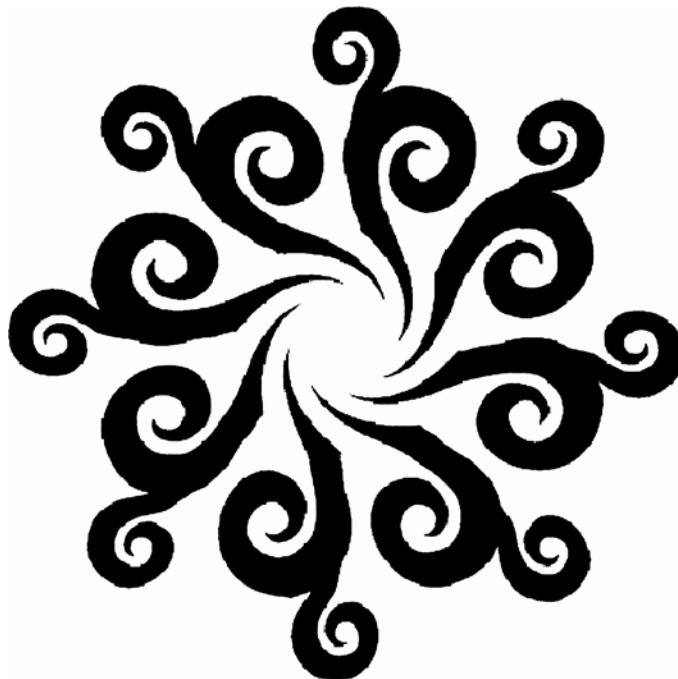
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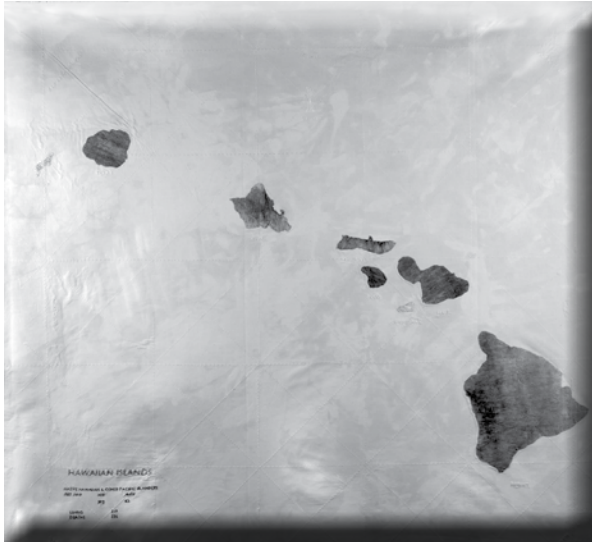


**INTRODUCTION**

Long before the “written” word was imposed on us, we spoke to one another with vivid stories and images. From the winter count buffalo hides of the Great Plains to the Khipu (knotted strings) of the Incas, in creative and diverse ways, we recorded the information we knew would be important to our descendents. As our world has changed, we now must learn new ways to pass on our story to the children who come after us, in a manner and language that is of this time and place.

It is for these reasons that the authors decided to use art as a component of this publication. NNAAPC commissioned four acclaimed and innovative Native American artists to produce original pieces. They were simply asked to think about the impact of HIV on Indigenous communities over the years, and the value of health information to facilitate healing and well-being. The artists were then given the freedom to work in any medium, to produce a piece of any size and content. These pieces have been captured in photographic form for this publication, and the artists were gracious enough to provide a description of their process and thoughts on the topic. We honor them not just for their contributions to this project, but for the legacy of stories and culture they are creating and sharing with us all. Art is a component of our healing as a people.

In honor of who we are and have always been, we share with you these stories and images that have been offered to this work by our Indigenous brothers and sisters.



### **Native Hawaiian Artist Bernice Akamine**

Bernice Akamine, a native Hawaiian artist, began to pursue a career in art later in life than many. Akamine chose to raise a family and then return to school for a degree; during her studies at University of Hawaii at Manoa she rediscovered art; deciding that doing what one loves is most important, she changed her major and was awarded a Bachelor of Fine Arts in glass and a Master of Fine Arts in sculpture and glass, both with honors. Akamine's work is in the permanent collection of the Peabody Essex Museum in Massachusetts, the Hawai'i State Foundation on Culture and the Arts, and Wright State University Art Galleries, Dayton, Ohio. She is recipient of an Award of Excellence, Fiber Hawaii 2003; Artist in Residence at the Smithsonian Institute, National Museum of the American Indian, New York City, 1999; and a 2010 Hawaii's Modern Masters at Luxury Row. Akamine is currently serving as a Community Scholar at the Smithsonian Institute, National Museum of Natural History, Washington, D.C.



### **Shawnee Artist Alistair Andrew Bane**

Alistair Andrew Bane is a citizen of The Eastern Shawnee Nation of Oklahoma. His father was an avid artist and architect, and Bane's earliest memories are of sitting next to his father painting and drawing. These early experiences developed into a lifelong love of the arts. Alistair later studied fine art and fashion design at The School of The Art Institute of Chicago. Today he works in a variety of contemporary and traditional media, including acrylics on canvas, mixed media, beadwork, quill work and ribbon work. His paintings often reflect the modern day experiences of Native Americans and the juxtaposition of traditional ways and the contemporary world. Bane currently makes his home in Denver. He pursues his passion for creating art full time.



### **Diné Artist Kirbieleya “Eyelash” Platero**

Kirbie Platero is a fierce 22-year-old Diné mother, graffiti/visual artist, social justice activist and poet. Her impressive reputation of art and activism is inspired and driven by both her amazing son Josiah – whom she gave birth to at age 17 – and her personal survival of sexual violence. Ms. Platero has promoted vital awareness and education around reproductive/family justice, substance abuse, sex education, domestic/sexual violence, incarceration, motherhood and community resiliency. Her creative expressions are personified through the marriage of genius, passion, stirring visual art and a pro-women-social-justice-conscience. Her dynamic talent encompasses an impressively broad range of artistic media, extending from graffiti and street art to painted canvases, mixed media art Photoshop, watercolor, colored pencil and ink.

At the age of 13, Ms. Platero discovered her talent as an artist and her passion for community-based feminism and advocacy of women of color. For years, she has served as the Program Graphic Artist for Albuquerque’s radical women of color organization, Young Women United. Serving as a full time volunteer at Young Women United, she provided her leadership and advocacy for upcoming youth and teen parents. In 2009, she received the Marie C. Wilson “Young Woman of Vision” Award for her organizational work on the city’s sexuality education campaign. She helped lead a successful effort of young New Mexican women of color to advocate before state officials, demanding the implementation of comprehensive sexuality education in Albuquerque public schools. Ms. Platero has continued to influence

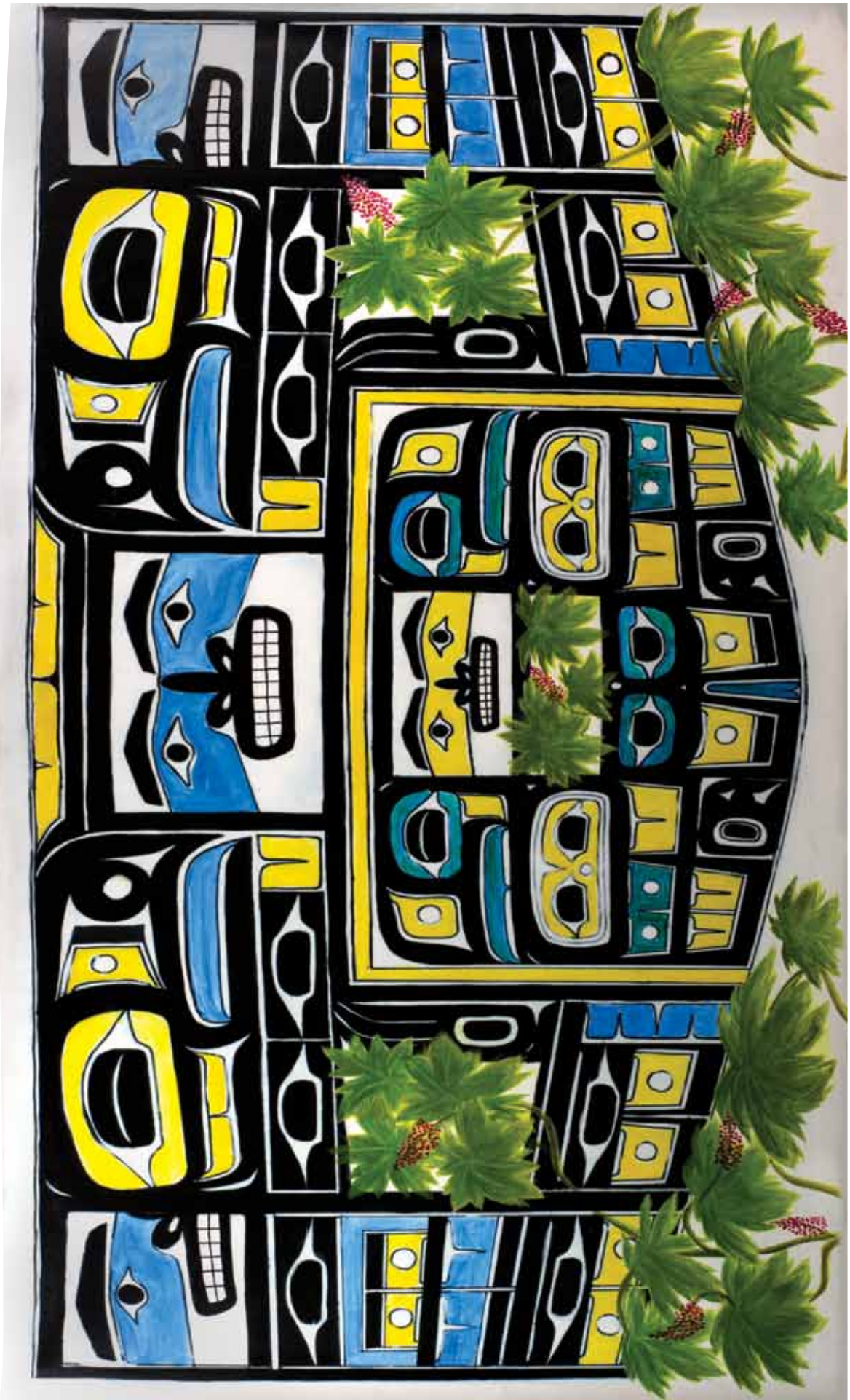
amendments to Albuquerque’s public health, educational and criminal justice policies through her artistic social critiques, exposing systemic inequities toward women of color.



### **Alaska Native Artist Clarissa Rizal**

Clarissa Rizal is a traditional Chilkat and Ravenstail weaver, teacher and facilitator. She specializes in design and creation of Tlingit regalia including *Chilkat* robes, Ravenstail weavings and button blanket robes. In 1973, Chief Harry K. Bremmer, Sr. from Yakutat, Alaska, introduced Clarissa to the art of the Tlingit Native dance regalia-making after teaching her traditional Native song and dance. In 1986, she apprenticed with the last of the traditional *Chilkat* weavers, Jennie Thlunaut, who passed away directly after the apprenticeship at the age of 96. Clarissa continues to fulfill her promise to Jennie that she help revive this ancient weaving by conducting workshops and apprenticeships. Clarissa authored “Jennie Weaves An Apprentice – A Chilkat Weaver’s Handbook,” which received the HAIL Award (Honoring Alaskan Indigenous Literature) in 2008. A founding board member of the non-profit arts organization, Artstream Cultural Resources ([www.artstream.net](http://www.artstream.net)), Clarissa is an “artist working for and with other artists.” She initiated and co-directed many of the projects and events on Artstream’s website including: The Northwest Coast Native Dance Regalia documentary; the Pagosa Pretenders Theater Co; Navajo and Chilkat weavers’ cross-cultural exchange; hosted the Whistlepig monthly house concerts featuring musicians/singer-songwriters from around the nation; and spearheaded the first Biennial Northwest Coast Native Artists’ Gathering and Evening Concert in May 2006. Self-employed since 1980, she also owned Kahtahah Landscape Gardeners in 1981-1993 and was co-owner of the online daily news source Pagosa Daily Post from 2004-09.





“Chilkat Devil’s Club” by Clarissa Rizal



## “Chilkat Devil’s Club” by Clarissa Rizal (Alaska Native)

“Native Americans used Devil’s Club (*Oplopanax horridus*) both as food and medicine. The plant was traditionally used to treat adult-onset diabetes and a variety of tumors. Devil’s Club is employed as a blood tonic, used in salves for skin ailments, rheumatoid autoimmune disease, cuts and bruises. For spiritual protective purposes, the stalks were shaved of their thorns and placed above doorways, made into beads and worn on the person; shaved stalk were also put in bowls and placed around the house. Sometimes Devil’s Club was dried and burned like an incense during certain spiritual ceremonies. In vitro studies showed that extracts of Devil’s Club inhibit tuberculosis microbes (Tai, J. et al 2006) Because it is related to American ginseng (*Panax quinquefolius*), some believe the plant helps the body’s adapt to stress and changing situations. The plant has been harvested for this purpose and marketed widely as “Alaskan ginseng,” which may damage populations of Devil’s Club and its habitat, which is why many Alaska Native peoples are very protective of our Devil’s Club population; we do not want the plant to disappear because of capitalist exploitation.

“The plant is covered with brittle yellow spines that break off easily if the plants are handled or disturbed, and the entire plant has been described as having a “primordial” appearance. Devil’s Club is very sensitive to human impact and does not reproduce quickly. The plants are slow growing and take many years to reach seed bearing maturity, and predominately exist in dense, moist, old growth conifer forests in the Pacific Northwest, which is why we will harvest only what is needed. There are times we will harvest the entire stalk if the need calls for this, otherwise, we will take a small cutting at the lower backside (the part that does not face the beach or face of the forest). To ensure the continuance of the Devil’s Club, we never harvest the entire plant.

“Devil’s Club generally grows to 3.5 to 5 feet tall; however, instances exist of it reaching in excess of 16 feet in rainforest gullies. I have literally walked under “forests” of Devil’s Club. The spines are found along the upper and lower surfaces of veins of its leaves, as well as the stems. The leaves are spirally arranged on the stems, simple, palmately lobed with 5 to 13 lobes, 8 to 16 inches across. The flowers are produced in dense umbels 4 to 8 inches in diameter; each flower is small, with five greenish-white petals. The highly poisonous fruit is a small red drupe 0.16 to 0.28 inches in diameter, elongate in clusters.

“Devil’s Club reproduces by forming colonies through a layering process. What can appear to be several different plants may actually have all been one plant originally, with the clones detaching themselves after becoming established by laying down roots.

“This species usually grows in moist, dense forest habitats, and is most abundant in old growth conifer forests. It is found from south-central Alaska and throughout southeastern Alaska, to western Oregon, western Alberta and Montana. Separate native populations also occur over 900 miles away in Lake Superior on Isle Royale and Passage Island, Mich., and Porphyry Island and Slate Island, Ontario. I personally have seen Devil’s Club here and there in the higher elevations in marshy areas of the San Juan Mountains surrounding Pagosa Springs, Colo.

### Design Description of “Chilkat Devil’s Club”

“The stylized *Chilkat* ceremonial robe design depicts a smaller *Chilkat* robe within a larger one, which is part of a series of robes portraying ‘a robe within a robe’ image. This particular theme is one that tells the story of the transference of indigenous knowledge healing methods from one

person to another, from one tribe to another, from one community to another, or from one culture to another; this is shown by way of the main human face (the Creator) who has gifted us the Devil's Club and is flanked by the human faces on the top and left corner of the main robe; they hold the smaller robe (center lower half outlined in the yellow/black border) showing the recipient (smaller human face) of healing knowledge and simultaneously the recipient of the healing. In this case, the Devil's Club signifies the ancient healing methodology of the indigenous peoples mainly of the Northwest Coast across the Northern part of the U.S. and southern Canada to Ontario. But because of small cottage industries in Alaska and Canada that are creating healing salves, teas and tinctures, the healing properties of Devil's Club is available to anyone in the world."



## PURPOSE OF THIS PROJECT

Health literacy is defined in Healthy People 2020 as the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions. (U.S. Department of Health and Human Services, n.d.). The discussion around health literacy tends to focus on individual capacity to understand information regarding health conditions and processes of care delivery in order to feel comfortable navigating the healthcare system and personal treatment options. This is clearly important – people need to know basic information in order to communicate effectively with their service provider and feel comfortable with the level of care they are receiving. The American Medical Association states the level of a person’s health literacy can be used to predict a person’s overall health more effectively than examining that person’s age, income, employment status, education level or race (American Medical Association, 1999).

But, what would happen if we broadened the scope of the definition and began to examine health literacy among larger populations? If we moved the application of health literacy from an individual level to a macro level. The definition might shift a little to read: “the degree to which a community has the capacity to obtain, process and understand health information and statistics, on the state of health and health services, in order to inform programmatic direction, strategic planning, and the portrait of community health and wellness.”

One might reasonably argue a definition like this better prepares communities to think about the broader impacts of health information and the nature of the information that can create these impacts. Poor health literacy has had serious human and economic consequences. Deficiencies in access to health information, services and technology can ultimately lead to lower usage rates of preventive services, less knowledge of chronic disease management, higher rates of hospitalization and poorer reported health status (Berkman, et al., 2004). Our tribes, corporations, clinics, departments and organizations can work to prevent these individual and communal consequences by working to understand and use the surveillance data available to us.

Public and tribal health practitioners regularly interact with community health data – whether in a graph in an article, a chart in an e-mail newsletter, or responding to a survey. However, there is an underlying assumption in disseminating this data – that all who read it are fully versed on the how to make use of epidemiological information.

Reports and statistics on the state of Human Immunodeficiency Virus and Autoimmune Deficiency Syndrome in American Indian, Alaska Native and Native Hawaiian communities are available; however, because the research conducted in our communities is infrequent, publication is sporadic and the number of Native researchers working in HIV is low, these articles and documents can be difficult to locate.

In a time of diminishing resources, fewer and fewer Native-specific HIV programs are surviving. There are more staff being forced to integrate HIV prevention work with other components of their mission (i.e., sexual assault, teen pregnancy, sexually transmitted diseases, community outreach). As HIV programs are disappearing, other health professionals are being asked to add HIV prevention to their already long list of responsibilities. There are also notoriously high levels of staff turnover in many tribal programs and equally notoriously low levels of resources available for staff development and ongoing support. All of these concerns dilute the level of HIV expertise available in our communities. This is why continuous training, technical assistance and capacity building should be made available to us.

This publication seeks to draw from the knowledge and skill already present within our communities to access and use HIV and AIDS epidemiological information, to increase knowledge of culturally responsive resources for Native and non-Native service providers, and to support efforts to become more informed consumers of health information. This publication will walk through the basics of epidemiological information so that Native-serving clinics, programs, community-based organizations, health departments, service providers and advocates are better equipped to obtain, process and understand the wealth of health data available. It should be said that this publication will focus on HIV and AIDS health data, but the framework is applicable to all areas of health (diabetes, obesity, tobacco, physical activity, aging, etc.)



## VALUE OF EPIDEMIOLOGICAL DATA TO HIV PREVENTION PROGRAMS

Although there were many mistakes that took place early in the AIDS epidemic, one positive step was the creation of a systematic way of collecting data on people living and being diagnosed with HIV or AIDS. There are still some flaws, however this surveillance system is now an invaluable cornerstone of the HIV prevention and treatment field.

Public health data are used by different consumers for different reasons, but below are some of the primary purposes.

- Monitor disease trends – Professionals and community members alike can access data to see where the disease is moving geographically and demographically. Questions like, “Who is at the greatest risk for HIV?” “What regions have the highest concentrations of HIV?” and “What age range has the greatest number of new HIV infections?” are all answered by HIV surveillance data.
- Evaluating the effectiveness of various HIV/AIDS programs – By examining the impact of collective HIV prevention methods (outreach, interventions, social marketing campaigns, condom distribution, testing and counseling, etc.) on HIV incidence and comparing it to disease trends, leaders can make more informed decisions on planning and prioritizing prevention programs. This is why certain interventions that target higher risk populations might be emphasized over those designed to reach lesser risk populations.
- Allocate resources – Once trends are identified, plans have been constructed and populations and/or areas are prioritized, decision makers allocate hundreds of millions of dollars in resources to target those areas or populations that seem to be the most impacted.
- Identifying new or unusual cases of HIV infection – HIV is most commonly transmitted through sexual or drug using

behaviors, but what would two new cases of mother-to-child transmission on a small reservation tell prevention providers? Perhaps that efforts need to be refocused on this uncommon method of transmission. Unusual cases of HIV transmission (e.g., occupational exposure, mother-to-child transmission, blood transfusions or organ donation) are considered rare in the U.S., however, they do still happen from time to time. Knowing this can help point to behavioral trends, gaps in prevention or education services, or the need to bolster universal precautions and biomedical prevention methods. The same can be said if a new strain of HIV is identified in a region. This may point to a shift in the epidemiology of a new strain and require doctors to re-examine medication schedules for current patients, and move prevention specialists to bolster efforts to talk about superinfection in their work with people living with HIV (PLWHA).

These are some examples of how data can be used on a larger scale, however, the exact same process can take place within a reservation, region, island, or even within an organization’s client base. Disease trends can be monitored locally to determine higher risk populations and to chart out where the disease is going. Then based on that information, programmatic decisions can be made on how to use staff time, what programs to put forth and how to reach these trending populations. Epidemiological information and surveillance data provide the foundation for many programmatic and funding decisions.

### **Why is This Important to Our Communities?**

In 2010 the White House released the National HIV/AIDS Strategy (NHAS), which set a new stage for HIV prevention and treatment. This strategy, among its listed recommended actions, clearly states the need for “federal and state agencies [to] consider efforts to support surveillance activities to better characterize HIV among smaller populations such as AAPIs [Asian Americans and Pacific Islanders] and AI/ANs [American Indians and Alaska Natives],”

and to support funding for groups “based upon the epidemiological profile within the jurisdiction” (Office of National AIDS Policy [ONAP], 2010).

Ironically enough, the document itself failed to report data on American Indian, Alaska Native, Native Hawaiian populations “because of small numbers” (ONAP, 2010).

These two different references to the National Strategy highlight why it is important for our communities to have easy access to accurate data – because without this level of control of data and how they are used, we are continually left out of the conversation. And in order to ensure this doesn’t continue to happen, communities, clinics, states and federal programs must strengthen local efforts to collect, understand and use Native-specific data to benefit the people, and advocate for quality programs that serve our communities.

#### *Understand Local, Regional and National Disease Trends*

All programs should be able to look at a statistical report, compare it to previous years or other geographic areas or against other demographic categories and construct a picture of how the disease is impacting the local Native community in relation to how it is impacting other groups and other areas.

#### *Inform Program and Administrative Decisions*

Programs can be effectively created, tailored or discontinued based on identified disease trends. Program administrators can look for staff, who carry certain expertise that matches the trends or the vision of the agency, and grant proposals can be submitted strategically.

#### *Share Accurate Information with the Community*

As Native service providers, we have an ongoing responsibility to the community we serve – to accurately and properly communicate relevant health information to community members and stakeholders in such a way that it makes sense and is usable. Understanding this epidemic – especially the local impact – will only serve to mobilize the community, and support our ongoing efforts to improve community health and wellness.

#### *Community Empowerment*

Having access and sharing good health information relevant to the community will inform our own health and ultimately impact behaviors that may, in turn, impact the health of our families. Further, our people will be in a better position to give an informed argument for culturally responsive programming.

#### *Skills Building*

The more providers examine and work with the data, the more skilled they will become. That expertise can become standard in an organization or department, and passed on to other staff members through internal training and interaction. The benefits become more widespread when we seek to learn a new skill, make the efforts to exercise it and pass it on.

#### *Create Local Efforts*

Working with data and understanding the benefits can bolster the efforts of local programs to create our own surveillance and evaluation systems to collect health information about the community and the people we serve. Simple demographic information can be collected, or more complex information about knowledge, attitudes, or behavior over time – all of which can be used to strengthen programs and inform decision-making processes.

#### *Reinforce Policy and Advocacy Work*

Whether it is policy work at the organizational, tribal or federal level, the availability of information drives health policy changes and initiatives. We are in the position to analyze data for policy makers so they can better understand the impact HIV and AIDS have on our communities, and ultimately take steps to address potential negative effects.





“Untitled” by Kirbieleya “Eyelash” Platero

## “Untitled” by Kirbieleya “Eyelash” Platero (Diné)

“When I began this project, I asked myself how I could relate to HIV positive community members and the ongoing epidemic of HIV. This canvas represents change and strength, and transforming one’s obstacles in life into positive stepping stones used to move forward in life resiliently. I am in awe and have much respect for the magnitude of strength HIV positive community members and their families embody, in the face of public misinformation and stigma regarding this virus. My appreciation comes from my own personal experiences with an equally misunderstood and stigmatized issue: sexual violence. As a result, I grew up with the self-understanding that I had been victimized as a child, and equally unfairly blamed for violence I had not wanted.

“In the same sense, I imagine HIV is not a wanted infection. For this reason, it is clear that both HIV and sexual violence exist hand in hand. Case in point, Native women endure the highest rates of sexual violence in the nation, while becoming the second fastest growing demographic in Indian Country at risk of HIV infection.

“This canvas thus tells a story about a small Indigenous girl who was comfortable in her own skin ... in a pink house... on the reservation... in the past. She finds peace in the cornfield that represents the present moment. The offering of corn is her acceptance of her past, as well as an offering she makes for her personal growth and resiliency. The city is downtown Albuquerque, representing her future and her intention of moving forward as the person she eventually grows into. Dedicated to our Native communities – both rural and urban – this canvas serves as a testament to the resilient capacity we as Indigenous peoples possess and must use to overcome even the most seemingly impossible challenges in life. For resiliency is our *birthright*.”

## CHALLENGES WITH NATIVE-SPECIFIC DATA

### Individual Data:

#### Racial Misclassification

Racial misclassification for American Indians and Alaska Natives (AI/AN) has profound impacts on the efforts of HIV prevention. When Native people who access HIV testing or treatment services are not accurately classified by tribe or Native group, it can affect the ways funding, resource allocation and community awareness are done.

Racial misclassification can create misconceptions in Native communities surrounding the visibility and impact of HIV/AIDS. Even though all HIV/AIDS diagnoses are reported to a public health surveillance system, the effects of racial misclassification can lead to underestimating the need for HIV-related services. Misrepresentation then adds to the denial many Native communities have about HIV/AIDS being a problem. HIV data that show low incidence and low prevalence inherently create a sense of

accomplishment and well-being – leading to a false sense of safety and perhaps even complacency. Messages such as “lower-risk population” or a focus on other racial and ethnic groups because they are the “most impacted,” reinforce a low sense of perceived susceptibility to HIV, and alter perceptions about the necessity to engage in lower risk behaviors. If a community is not presented as being at risk, they may not take protective steps in education or lowering risk behaviors – individually or as a community.

Now more than ever funding decisions are being directed by epidemiological information. Funding streams are linked directly to HIV testing positivity rates, HIV incidence and AIDS cases. With AI/AN cases being classified in other racial categories, Native targeted services can go underfunded. Accurate coding of HIV/AIDS data among American Indians and Alaska Natives is crucial to making sure resources for HIV-related services go to AI/AN-serving health care facilities. Numbers are driving funding decisions, and inaccurate data will

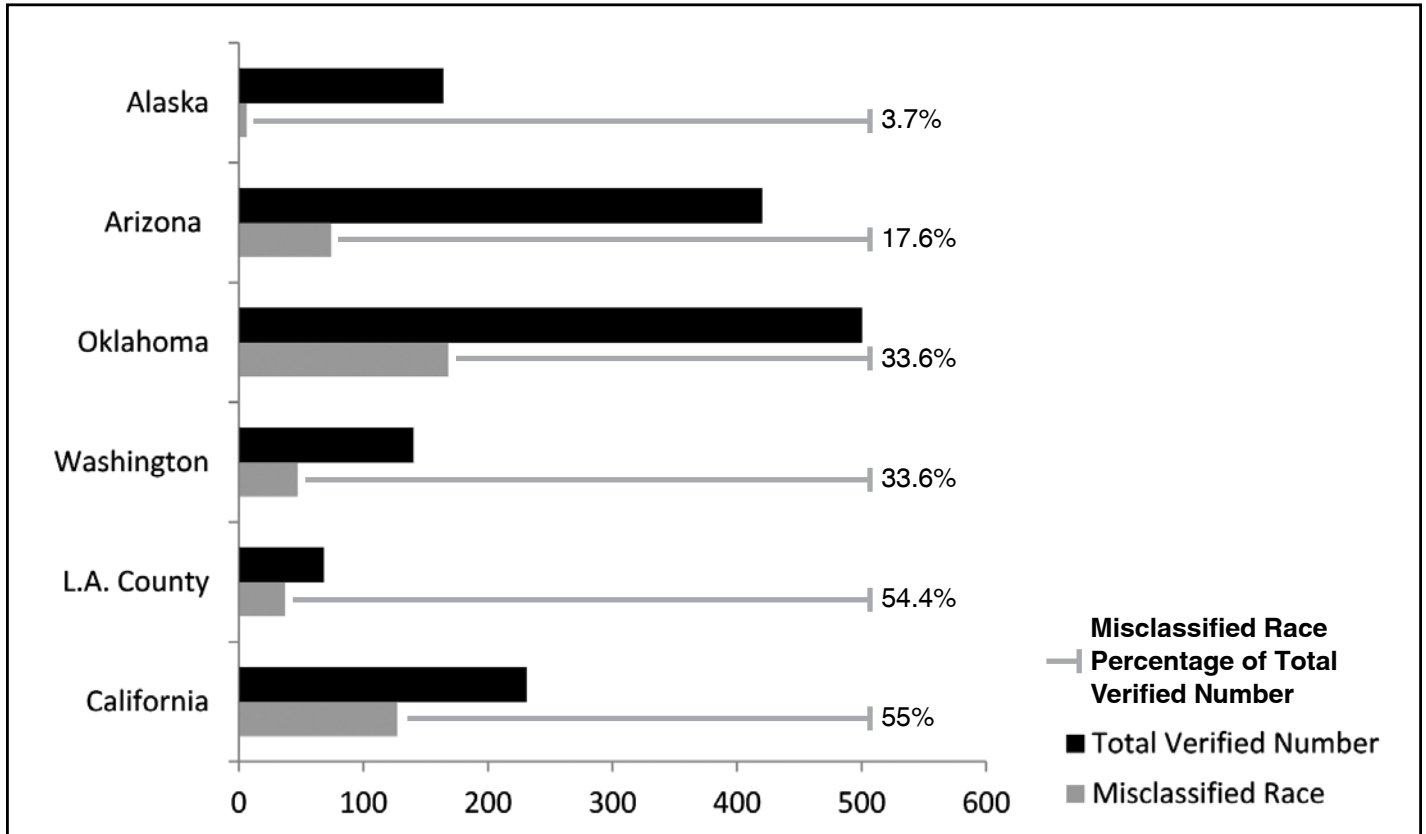


Table 1 - Percentage race misidentification of AI/AN people reported to HARS compared to total number reported, by site 1984–2002 (based on Bertolli, J., Lee, L., et al 2007)

lead decision-makers to allocate funding to other populations perceived to be at higher risk.

But gathering accurate data on race is complex in Indian Country. A 2007 public health report (Bertolli, J., Lee, L., et al 2007) looked at AI/AN numbers reported to the HIV/ AIDS Reporting System (HARS), and cross-referenced with IHS numbers, across five states and one urban area. Racial misclassification was highest in California – 127 of 231 (55 percent) AI/AN HIV cases. This number was compared with racial misclassification in Alaska, where the Native population is visible (more than 19 percent of the population) and health services are more integrated across locations. Of the 164 HIV/ AIDS cases in Alaska, only six (3.7 percent) were misidentified. These results may indicate that the larger the presence of American Indians/Alaska Natives, the greater the likelihood of correct racial identification. Results may also be due to several factors: client confusion or unfamiliarity with racial categories, inaccurate perceptions of client's race by service providers (where the provider classified race for the client), hesitancy of some Natives to accurately report their tribal affiliation when seeking HIV/AIDS services, and differences in categories across various agency forms used.

It is therefore difficult to rely only on national or state data to represent what is going on with the vast diversity of our communities.

### **Self-Identification of Natives**

Although the latest U.S. Census Bureau statistics report the Native population as 4.5 million, the number of those who are enrolled in federally recognized tribal nations is closer to 2 million (Bureau of Indian Affairs 2012). Both numbers are used to plan services and allocate resources, yet they answer very different questions. Self identification varies based on how the question is asked – self-report for the census or tribal-specific blood quantum criteria for membership. Which type of data used impacts services, especially those that are tribal specific or tied to federal funding. It can also determine which services an individual qualifies for.

Racial and ethnic data that include self-identification come directly from the categories and options used. Federal guidelines for collecting data on race and ethnicity use only six categories – “American Indian or Alaska Native,” “Asian or Pacific Islander,” “Black,” “White,” “Hispanic” or “Not of Hispanic Origin.” These categories do not make distinctions between vastly different cultural groups – Native Hawaiians and Nepalese, for instance. Health issues related to specific historical or cultural factors can be hidden in these broad categories, and affect public and local perception of who may be at risk for HIV or other health concerns.

Self-identification also varies with the individual. Many people of mixed heritage, for instance, may prefer to report in as many categories as apply on census or other forms. (Johnson, J., Jobe, J, et al, 1996). Native people who are multi-tribal often do not have the opportunity to report multiple race or tribal affiliations. For example, BIA guidelines only allow Natives to enroll in one tribal nation. As a result, demographic information from the BIA shows a very different picture of Native populations than the U.S. Census, which allows for not only multiple race and ethnicities, but identification of specific and multiple tribal affiliations. Reports from the CDC generally only allow for one racial or ethnic identification as well, although organizations can choose to add a space for individuals to self-report their tribal affiliation or choose “Other.”

### **Aggregated data:**

#### **Distinct tribal cultures**

There are currently 565 federally recognized tribes within the continental United States, as well as Hawaii and Alaska, while there are hundreds more that are state-recognized and non-recognized (Bureau of Indian Affairs, 2012). Even the word “tribe” is not universal when referring to groups of Native people. From region to region, various terms are used, including, but not limited to bands, rancheros, villages and clans. Each of these Native entities has distinct cultures, beliefs, social norms, etc. And even within these entities, these aspects can vary from place to place, community to community, family to family and even person to person. While there are some commonalities in values and shared experiences, they are not universal. With that being

said, assessments, studies and research cannot be generalized across all Native communities and people, including and particularly epi data.

### **Tribal-specific data**

One unique aspect of aggregated Native-specific data is tribal sovereignty and data owned by individual tribes. Many, but not all, tribal health departments not only gather their own data, but closely guard how that data is distributed and used. Sovereignty and requirements for reporting are often complex issues. How data is reported depends on the specific requirements and agreements with each individual tribe, and the particular needs of the funding agency. Tribal data may not be included in overall aggregate numbers unless there is a specific data-sharing agreement (DSA) or other collaboration agreement in place. (CDC, 2012d) (See Case Study on DSAs, page 45) In cases where a tribe is part of a federal or state funded research project, if a DSA is used, data gathered are sometimes only reported in aggregate with no tribe specifically identified – “Native Americans in Arizona” for instance.

Since tribes, states and organizations vary greatly in how and when data is shared, especially sensitive health data, it is best to contact the particular tribe or tribal health department for their guidelines and policies, or to request information. (See Resources section).

### **States with name-based reporting**

While all 50 states in the United States, the District of Columbia, and six dependent areas—American Samoa, Guam, the Northern Mariana Islands, Palau, Puerto Rico and the U.S. Virgin Islands – use confidential name-based reporting to collect HIV surveillance data, there are currently only 46 states and five U.S. dependent areas that are reported in the Centers for Disease Control and Prevention (CDC) surveillance report, which is the main national surveillance data collected and distributed on HIV incidence and prevalence. This is because the CDC only includes those states that have been reporting confidential name-based reporting for at least four years. While this is a significant number of states, relative to those within the United States, until 2010 CDC reports left out states with large populations of Native Americans, Alaska Natives and Native Hawaiians, including California, Montana, Oregon

and Washington. This creates a false sense of awareness of how the HIV/AIDS epidemic affects Native people on a national level. The statistics, numbers and rates most often cited and considered definitive, may not truly represent how Native people are actually experiencing the disease.

The CDC also aggregates the data to combine American Indians and Alaska Natives. While they recently disaggregated Native Hawaiian data from Asians and other Pacific Islanders, in combining the data for American Indians and Alaska Natives, the rates are not accurately reflected for these distinct populations. Additionally, prior to the disaggregation of Native Hawaiian data from the Asian and other Pacific Islanders, this category was listed as having the fourth highest rate of new HIV infections, behind American Indians/Alaska Natives. When Native Hawaiians were separated from Asian and other Pacific Islanders, it showed their rate was actually higher than that of American Indians/Alaska Natives, becoming third, and dropping AI/AN to fourth.







## WHERE TO FIND THE DATA

There are many opportunities to access Native-specific data, but often starting a search can seem insurmountable; refining the search for data that applies to a particular community can be frustrating. But new initiatives hold some promise for better surveillance and reporting – the CDC working group for data on American Indian and Alaska Native communities, IHS congressional report on HIV in Indian Country and the recommended action in the National HIV/AIDS Strategy for, “Federal and State agencies [to] consider efforts to support surveillance activities to better characterize HIV among smaller populations such as AAPIs and AI/ANs” (Office of National AIDS Policy, 2010). All these efforts are focused on conducting accurate and appropriate surveillance activities. Hopefully, these additional resources will ease the process of hunting for relevant and useful data, as all of these activities will include methods of sharing this information with all interested parties.

However, there are still many resources currently available to consumers. This chapter provides some tips and some specific online sites for locating Native-specific and national/state/local HIV and AIDS data and resources.

### National v. Local Data

HIV data collected and presented on a national level is accessible and widely available to prevention workers. The CDC, Kaiser Family Foundation, IHS, Planned Parenthood, and Substance Abuse and Mental Health Services Administration (SAMHSA) all put out regular reports based on information collected on a national scale. The National Library of Medicine (NLM) houses this data as well as a wealth of journal articles. These are the types of statistics most often cited and used to justify national decisions.

The advantages of accessing and using these data are obvious. It is easily accessible – for example the

CDC maintains a standard site to house its annual report, <http://www.cdc.gov/hiv/topics/surveillance/resources/reports/index.htm>.

The data have already been reviewed by several sources – when national reports are released, you can generally be assured they have been examined by teams of skilled epidemiologists and statisticians. Because of this and the status of the various national groups releasing the reports, the data are generally accepted as valid and reliable.

The data in national reports are already laid out in charts and tables, and usually include an executive summary to provide highlights.

The data are shared among many stakeholders – reports are released far and wide, and often times generate media attention. For this reason, statistics shared in the reports are generally not a surprise to people, and statements made about reports are easily checked and validated.

A large sample helps to guarantee confidentiality – when the report speaks to hundreds of thousands of people, the confidentiality of those represented by the report is secure.

Some of the predominant national systems for collecting national level data

(all conducted by the CDC) on HIV include (CDC, 2012b):

- MMP (Morbidity Monitoring Project [or Medical Monitoring Project]) is a newer surveillance system designed to collect information from HIV/AIDS patients who received care from randomly selected HIV care providers.
- NHBS (National HIV Behavioral Surveillance System) began in 2003 collecting data on MSM, IDUs and heterosexuals at high risk in large urban areas with high levels of AIDS, by conducting surveys with members of the

population to determine their risk behavior, testing behavior and use of prevention services.

- HITS (HIV Testing Survey) primarily interviewed adults who were not HIV-infected but were at high risk for HIV infection. HITS collected information about what motivates people to get tested for HIV and what behaviors place people at risk for HIV.
- Monitoring HIV Counseling and Testing Behavior examines the data collected through the documentation of routine HIV tests collected during each CDC-funded HIV counseling and testing session. This is only for sites that receive CDC (or state health department) funding, and use the CDC-approved forms and reporting systems. Data collected include demographic, risk population and risk behaviors.

However, there are many reasons why organizations, tribes and Native health departments should not rely upon national data and reports alone.

- May not specifically break down the data on American Indian, Alaska Native and Native Hawaiian populations.
- May not calculate rates, or percentages compared to other groups to show possible health disparities; consumers of data may need to get out their calculators and do some of their own number crunching to uncover how the epidemic is impacting their communities versus other populations. Reports are generally constructed to outline the facts, and it is up to the consumer to take the information and use it.
- National data do not show the local impact of HIV or AIDS.

For these reasons, Native consumers of HIV and AIDS data should be prepared to look at local data. Data on HIV are collected by tribal clinics and hospitals, IHS clinics and hospitals, urban Indian

health clinics, private and public hospitals, STD clinics, family planning clinics, and local, county and state health departments. All of these organizations may also release regular reports on the state of the epidemic within their area. State health departments regularly report on HIV and AIDS cases per county – this can also be a very useful tool for providers to show local impact. Tribal data may be available to show a need on a particular reservation.

Accessing local data will allow prevention providers to:

- Better define the local impact
- Identify local at risk (or high risk) groups
- Target and prioritize local intervention planning to ensure greatest impact
- Help ensure local funds are being spent to address the local impact of the epidemic
- Communicate a sense of local acknowledgment and response to the epidemic

For example, accessing the HIV testing data from the local urban STD clinic may demonstrate that 5 percent of the total HIV tests performed within a year are with American Indian people, whereas clinic data show that 15 percent of the overall patient data population is American Indian. This may highlight a need to work with clinicians on how they discuss HIV with their Native patients or a need to educate the local community about the importance of HIV testing.

There are many groups that can help with locating or interpreting national data, and people should not hesitate to ask for assistance. Some of these groups may also produce their own reports, generate their own health data and publications.

- National Native American AIDS Prevention Center (NNAAPC) ([www.nnaapc.org](http://www.nnaapc.org))
- National Indian Health Board (NIHB) ([www.nihb.org](http://www.nihb.org))
- National Council of Urban Indian Health (NCUIH) ([www.ncuih.org](http://www.ncuih.org))
- National Association of State and Territorial AIDS Directors (NASTAD) ([www.nastad.org](http://www.nastad.org))

- National Association of County and City Health Officials (NACCHO) ([www.naccho.org](http://www.naccho.org))
- Urban Coalition for HIV/AIDS Prevention Services (UCHAPS) ([www.uchaps.org](http://www.uchaps.org))
- National Minority AIDS Council (NMAC) ([www.nmac.org](http://www.nmac.org))

Native organizations and tribes should take steps to collect our own quantitative data, if we are not already, and should also not shy away from collecting our own qualitative data that will help to better understand the impact and nature of the local epidemic.

### **National Level Data**

#### *Centers for Disease Control and Prevention*

The CDC is the entity responsible for the majority of HIV and AIDS surveillance conducted in the United States and its dependent territories. Within the National Center for HIV/AIDS, Viral Hepatitis, STD and TB Prevention (NCHHSTP) ([www.cdc.gov/nchhstp/](http://www.cdc.gov/nchhstp/)), there are many divisions and branches that process data and produce various reports or publications. Some CDC webpages of particular note are:

- CDC's HIV homepage (<http://www.cdc.gov/hiv/>) contains links to fact sheets, newsletters, podcasts, statistics, surveillance reports and other topics of interest.
- HIV/AIDS Statistics homepage ([www.cdc.gov/hiv/topics/surveillance/index.htm](http://www.cdc.gov/hiv/topics/surveillance/index.htm)) contains broadcasts, statistics, explanations of the surveillance system and links to various current and past HIV/AIDS surveillance reports. This is where you will find the CDC's annual comprehensive HIV/AIDS surveillance report. This is also where you will find ...
- National Prevention Information Network (<http://cdcpin.org/>) is a contracted program of the CDC. Their job is to collect prevention and treatment related materials that have been created by the CDC or its grantees for direct dissemination. On this site you will find published CDC guidances and

recommendations, articles, brochures and reports. You will also find links to relevant organizations, testing site locator, upcoming conferences, available funding opportunities and downloadable materials for reproduction.

- Division of HIV/AIDS Prevention (DHAP) homepage ([www.cdc.gov/hiv/aboutDHAP.htm](http://www.cdc.gov/hiv/aboutDHAP.htm)) is an introduction to the division within the CDC that is primarily responsible for researching, funding and overseeing the majority of the prevention programs in the country. There is also a link to articles published by DHAP staff (which provides some information and insight into some of the latest thoughts on the prevention field in the US).
- NCHHSTP Atlas ([www.cdc.gov/nchhstp/atlas](http://www.cdc.gov/nchhstp/atlas)) is an interactive tool to for accessing HIV, viral hepatitis, sexually transmitted disease (STD) and tuberculosis (TB) data collected by the CDC. This tool is a useful and educational way to access data, observe trends and patterns and to create detailed reports, maps and other graphics. Currently, the Atlas provides interactive maps, graphs, tables and figures showing geographic patterns and time trends of HIV, AIDS, chlamydia, gonorrhea and primary and secondary syphilis, TB and viral hepatitis surveillance data.
- NCHHSTP state profiles homepage ([www.cdc.gov/nchhstp/stateprofiles/usmap.htm](http://www.cdc.gov/nchhstp/stateprofiles/usmap.htm)) has a breakdown of HIV, chlamydia, gonorrhea, tuberculosis and viral hepatitis data by each state. Each state has its own profile that is published on this page based upon data gathered by the CDC.
- National Center for Health Statistics (NCHS) homepage (<http://www.cdc.gov/nchs/hus.htm>) is the launching point to exploring all of the CDC's stores of health data collected from multiple centers. There are data on everything from HIV/AIDS to health insurance, from syphilis to disability.
  - The NCHS has a page dedicated to American Indian and Alaska Native

health statistics (<http://www.cdc.gov/nchs/hus/american.htm>).

- Data for Native Hawaiians are still categorized under the label of Asian American and Pacific Islanders (<http://www.cdc.gov/nchs/hus/asian.htm>).

### *National Library of Medicine (NLM)*

The National Library of Medicine ([www.nlm.nih.gov](http://www.nlm.nih.gov)) is a repository funded by the National Institutes of Health and housed in Bethesda, Md. It is the world's largest medical library and collects materials, and provides information and research services in all areas of biomedicine and health care. NLM will house published reports, but serves as a more valuable resource for the published journal articles on various studies. Too often, those working outside of hospitals or academic institutions are not regularly exposed to journal publications. Peer-reviewed, professional journals are seen as the primary, professionally accepted method for sharing research results. As such, they are the resource for the most up to date information on topics such as HIV research, prevention practices, organizational development, program adaptations, and behavioral social determinants of health. Journal articles are published on both quantitative and qualitative research and on both biomedical and behavioral sciences. There is a physical library open to the public on the NIH campus in Bethesda, as well as online. The NLM website offers many links and search tools:

- Find, Read and Learn – this is the quickest and most direct resource. The link is located on the homepage. From here, you can:
  - Search for articles published in biomedical literature (using PubMed; the search is free, but may not produce access to the full text articles for free).
  - Search for the meaning of various medical terms (using free access to five different online medical dictionaries).
  - Search the collections of NLM (using

the LocatorPlus search engine, a person can search the books and articles housed in NLM and make requests for materials from the library).

- Read about different diseases (searchable by name of the condition, classification of the disease, affected bodily system, or the affected population).
  - Learn about different prescription drugs, supplements and herbs (including side effects, dosages, interactions and uses).
  - Locate a clinical trials (using [ClinicalTrials.gov](http://ClinicalTrials.gov), a person can find out the details and results of various clinical trials on various conditions – both past or present).
  - Locate free, full text journal articles (using PubMed Central database).
- NLM offers access to seven different search databases that allow you to look for journal articles, clinical trials, information on poisons and hazardous chemicals,
    - PubMed/MEDLINE ([www.ncbi.nlm.nih.gov/pubmed/](http://www.ncbi.nlm.nih.gov/pubmed/)) is one of the field's largest and most widely used search database for published articles of medical science, life sciences, social science, pharmacological and public health interest. There is an online tutorial to help novices conduct the most efficient searches. Searches will lead you to article citations, but may not necessarily allow you to access the full text article for free.
    - MeSH ([www.nlm.nih.gov/mesh/meshhome.html](http://www.nlm.nih.gov/mesh/meshhome.html)) stands for Medical Subject Headings and is a search engine designed to locate information based upon medical key terms or phrases.
    - UMLS ([www.nlm.nih.gov/research/](http://www.nlm.nih.gov/research/)

umls/) stands for United Medical Language System and is a resource for medical professionals. The UMLS integrates and distributes key terminology, classification and coding standards and associated resources to promote creation of more effective and interoperable biomedical information systems and services, including electronic health records.

- ClinicalTrials.gov (<http://clinicaltrials.gov>) is a registry and results database of federally and privately supported clinical trials conducted in the United States and around the world on any condition or drug. It includes information about a trial's purpose, who may participate, locations and phone numbers for more details.
- MedLinePlus ([www.nlm.nih.gov/medlineplus/](http://www.nlm.nih.gov/medlineplus/)) is a website for patients, friends and family members to research and learn about diseases, conditions and wellness issues. The website uses common, non-medical language and provides reliable, up-to-date health information for free.
- ToxNet (<http://toxnet.nlm.nih.gov/>) links to you another webpage that houses various databases on toxicology, hazardous chemicals, environmental health and toxic releases.
- LocatorPlus (<http://locatorplus.gov/>) find books and journal articles, and request materials housed within NLM for free.
- NLM also hosts a project called Native Voices: Native Peoples' Concepts of Health and Illness (<http://www.nlm.nih.gov/nativevoices/>). This project includes a wonderful website, interviews and art display that honor the interconnectedness of wellness, illness and cultural life for American Indians, Alaska Natives and Native Hawaiians. It is

meant to convey Native concepts of health and illness are based in our close connections to community, spirit and the land. This project began in 2003 when NLM undertook a new strategy to enhance outreach programs for Native American communities. They conducted a series of listening circles where NLM officials met with tribal leaders and elders in their home settings, to discuss their needs for access to health information resources, and what support NLM might be able to provide. These circles were convened in North Dakota, Alaska and Hawai'i and included site visits to educational and cultural venues that helped the team to appreciate first-hand the historical and contemporary influences on Native views on wellness and illness. Over a period of several years, additional consultations and visitations to reservations, remote villages and urban health facilities in the Lower 48 states, Alaska and Hawai'i explored prospective topics, issues and themes that ultimately led to the contents of the exhibition.

The Native Voices Project provided NNAAPC with the inspiration for this publication and to reach out to Native artists to create original pieces of art that help to tell the story of health, healing and sharing information in order to preserve wellness.

Highlights of the exhibit include:

- Healing Ways ([www.nlm.nih.gov/nativevoices/exhibition/healing-ways/index.html](http://www.nlm.nih.gov/nativevoices/exhibition/healing-ways/index.html)) is a site where visitors will hear the voices of American Indians, Alaska Natives and Native Hawaiians as they tell their stories and express their ideas about health (including ceremonies, illness, community role in wellness preservation, medicine plants, traditional games, the impact of disease and Navajo Code Talkers).
- Hōkūle'a ([www.nlm.nih.gov/](http://www.nlm.nih.gov/))



- nativevoices/exhibition/hokulea/index.html) is a series of pages that recognize the role Native Hawaiian voyaging canoes played, and continues to play, in the Hawaiian way of life.
- Healing Totem ([www.nlm.nih.gov/nativevoices/exhibition/healing-totem/index.html](http://www.nlm.nih.gov/nativevoices/exhibition/healing-totem/index.html)) are web pages describing both the significance and meaning of the totem that sits in the gardens of the National Library of Medicine (as designed and carved by master carver Jewell Praying Wolf James [*Lummi*]) as a symbol of good health and healing and the role that traditional totems played in telling stories, communicating information and maintaining cultural values.
  - Art Gallery ([www.nlm.nih.gov/nativevoices/exhibition/art-gallery/index.html](http://www.nlm.nih.gov/nativevoices/exhibition/art-gallery/index.html)) is a display of original works by Native artists depicting Native healing and wellness. Some artworks are specifically focused on healing, but ceremonies and objects that serve other purposes can also have a healing aspect. The artists represented in the gallery draw represent a diversity of styles and subjects, of cultures and media, as well as the diverse healing practices and health issues faced by different cultural groups.
- Fact sheets
  - HIV testing promotional materials
  - HIV testing initiative partner sites – an interactive map of the sites participating in the expanded testing effort.
  - Training provides links to a variety of online and live training materials and opportunities.
  - Toolbox provides a listing of assessment and risk reduction tools and resources.

The HIV/AIDS Program at IHS, in collaboration with the IHS Division of Epidemiology, has also been successful in the past securing funding to support the National Knowledge/Attitude/Behavior (KAB) Survey and will occasionally produce reports or post links to the results of the survey. IHS will also periodically produce reports for Congress and other governmental entities on the state of the AIDS epidemic in Indian Country; the data for these reports are culled from their own HIV prevention, counseling and testing, research and outreach/education programs, as well as other available surveillance materials. IHS may be able to satisfy special requests for specific data on both the national and local level.

Besides the NLM, CDC and IHS, most governmental agencies and many national non-profits also produce reports, articles, newsletters, conduct surveillance activities, host blogs, produce podcasts and a variety of other methods to convey valuable health data. It may take some time to work through these large websites or these large agencies to find the various offices, centers, divisions, or projects that produce or house such publications, but most sites feature an internal search engine that will allow visitors to quickly conduct some searches for the desired information.

- Substance Abuse and Mental Health Services Administration (SAMHSA) ([www.samhsa.gov](http://www.samhsa.gov))
- Health Resources and Services Administration (HRSA) ([www.hrsa.gov/index.html](http://www.hrsa.gov/index.html))
- Office of Minority Health (OMH) ([minorityhealth.hhs.gov](http://minorityhealth.hhs.gov))
- Office of Minority Health Resource Center

### *Indian Health Service (IHS) HIV/AIDS Program*

The Indian Health Service has a congressionally mandated position and office that oversees the operation, funding and evaluation of its HIV/AIDS service, prevention and research programs. Their website ([www.ihs.gov/MedicalPrograms/hiv aids/](http://www.ihs.gov/MedicalPrograms/hiv aids/)) is extensive and features the following components:

- AI/AN Research is a link that houses relevant, full-text publications, journal articles and reports on HIV in Native communities.

(OMHRC) ([minorityhealth.hhs.gov](http://minorityhealth.hhs.gov))

- National Institute of Health (NIH) ([www.nih.gov](http://www.nih.gov))
  - National Institute of Allergy and Infectious Diseases (NIAID) ([www.niaid.nih.gov/](http://www.niaid.nih.gov/))
- Office of HIV/AIDS and Infectious Disease Policy (OHAIDP) ([www.hhs.gov/ash/ohap/index.html](http://www.hhs.gov/ash/ohap/index.html))
- Office of National AIDS Policy (ONAP) ([www.whitehouse.gov/administration/eop/onap](http://www.whitehouse.gov/administration/eop/onap))

There are several other national and local non-profit organizations that also regularly conduct their own surveillance, surveys and research on the state of HIV and AIDS in the U.S.

- Kaiser Family Foundation (<http://www.kff.org/hivaids/index.cfm>)
- Robert Wood Johnson Foundation ([www.rwjf.org/](http://www.rwjf.org/))
- Planned Parenthood ([www.plannedparenthood.org/](http://www.plannedparenthood.org/))
- American Foundation for AIDS Research (AMFAR) ([www.amfar.org](http://www.amfar.org))
- National AIDS Treatment Advocacy Project (NATAP) ([www.natap.org](http://www.natap.org))
- National Association of People with AIDS (NAPWA) ([www.napwa.org](http://www.napwa.org))
- AIDS United ([www.aidsunited.org](http://www.aidsunited.org))
- National AIDS Housing Coalition (NAHC) (<http://nationalaidshousing.org/>)
- Gay Men's Health Crisis (GMHC) ([www.gmhc.org](http://www.gmhc.org))
- San Francisco AIDS Foundation (SFAF) ([www.sfaf.org](http://www.sfaf.org))
- AIDS Project Los Angeles (APLA) ([www.apla.org](http://www.apla.org))
- National Hepatitis C Coalition ([nationalhepatitis-c.org/](http://nationalhepatitis-c.org/))
- National Hepatitis C Advocacy Council ([www.hepcnetwork.org/](http://www.hepcnetwork.org/))
- North American Syringe Exchange Network (NASEN) ([www.nasen.org](http://www.nasen.org))

And international organizations may also provide

helpful resources for both international data and national level information.

- International Indigenous Working Group on HIV & AIDS (IIWGHA) ([www.iiwgha.org](http://www.iiwgha.org))
- Joint United Nations Programme on HIV/AIDS (UNAIDS) ([www.unaids.org](http://www.unaids.org))
- World Health Organization (WHO) ([www.who.int/](http://www.who.int/))

### **Native-specific Data**

There are many excellent resources for health data specific to Native populations and communities – whether reservation, rural, island or remote. Some of the organizations below have already been mentioned, but bear repeating here. By working with other Native organizations or researchers, you are supporting Indigenous-directed research, and can help to ensure the research and/or data were collected and used in a respectful manner.

- National Native American AIDS Prevention Center (NNAAPC) ([www.nnaapc.org](http://www.nnaapc.org)) works on research projects examining behavioral interventions, community attitudes and perceptions of HIV and effective prevention strategies. They also have a clearinghouse of publications, resources, social marketing materials and a calendar of upcoming conferences and trainings.
- National Indian Health Board (NIHB) ([www.nihb.org](http://www.nihb.org)) represents the health interests of all American Indian and Alaska Native tribes through legislative and policy action. They also have a public health department that runs several health and wellness projects, releases reports on the state of public health in Indian Country and hosts an annual Native public health summit.
- National Council of Urban Indian Health (NCUIH) ([www.ncuih.org](http://www.ncuih.org)) is an organization representing the health care interests of American Indians and Alaska Natives living in urban settings. They have an active research and technical assistance department that produces reports, conducts research and brokers resources.
- IHS HIV/AIDS Program ([www.ihs.gov/](http://www.ihs.gov/))

Medical Programs/HIV/AIDS) is the national program within IHS that oversees the operation, funding and evaluation of its HIV/AIDS service, prevention and research programs. They also work closely with the NIH's NARCH program.

- Native American Research Centers for Health (NARCH) (<http://www.ihs.gov/Research/index.cfm>) are different centers based in a collaboration between the IHS and the National Institute of General Medical Sciences (NIGMS) of the National Institutes of Health. The NARCH initiative, started in 2000, supports partnerships between AI/AN Tribes or Tribally-based organizations and institutions that conduct intensive academic-level biomedical, behavioral and health services research
- Alaska Native Tribal Health Consortium (ANTHC) ([www.anthc.org](http://www.anthc.org)) is a tribal health organization managed by Alaska Native tribal governments and their regional health organizations with many branches and programs that collect and process data, including a division of community health services, and an HIV and STD program.
- Urban Indian Health Institute (UIHI) ([www.uihi.org](http://www.uihi.org)) is a division of the Seattle Indian Health Board that specifically conducts research and produces reports on the status of the health on Urban Indians, including several projects involving infectious diseases
- Project Red Talon ([http://www.npaihb.org/epicenter/project/project\\_red\\_talon/](http://www.npaihb.org/epicenter/project/project_red_talon/)) is a program of the Northwest Portland Area Indian Health Board that provides technical assistance and resources for STD prevention
- Papa Ola Lokahi ([www.papaolalokahi.org](http://www.papaolalokahi.org)) is an organization in Hawaii that seeks to improve the health status and wellbeing of Native Hawaiians and others by advocating for, initiating and maintaining culturally appropriate strategic actions. Their website has a feature called the Coconut Wireless which is a clearinghouse for data on Native

Hawaiian health.

- National Congress of American Indians (NCAI) ([www.ncai.org](http://www.ncai.org)) has a health caucus and releases several health reports each year
- University Research Programs – There are a number of established research programs that consist of Native American researchers conducting research on health, HIV prevention, lesbian/gay/bisexual/transgender/queer/two spirit (LGBTQTS) issues and behavior change in Native communities.
  - American Indian Institute at the University of Oklahoma ([www.aii.outreach.ou.edu/](http://www.aii.outreach.ou.edu/))
  - National Center for American Indian and Alaska Native Mental Health Research at the University of Colorado Denver ([www.ucdenver.edu/academics/colleges/PublicHealth/research/centers/CAIANH/Pages/CAIANH.aspx](http://www.ucdenver.edu/academics/colleges/PublicHealth/research/centers/CAIANH/Pages/CAIANH.aspx))
  - Department of Ethnic Studies at Colorado State University (<http://ethnicstudies.colostate.edu/>)
  - Indigenous Wellness Research Institute at University of Washington ([www.iwri.org](http://www.iwri.org))
  - Center for American Indian Health at Johns Hopkins University ([www.jhsph.edu/caih/](http://www.jhsph.edu/caih/))
  - Tribal colleges and universities may also be running HIV/AIDS or wellness programs and can be a valuable resource for data, information and opinions. For example, schools like Salish Kootenai College, Diné College, Stone Child College and Wind River Tribal College all have or had HIV prevention programs in operation.

All programs and organizations collect some level of information about delivery of their services and who is receiving them – so gathering demographic and process level information can be relatively easy. It may include building a relationship with

the organization, explaining your request and then following any requirements they establish. These are natural steps in requesting information that may be of a sensitive nature, and it is also a way to respect the sovereignty of the tribe, village or group that is sharing it. Below are some suggested groups you may want to contact for access to their database:

- Tribal Health Departments – including community health representative programs, health education programs and community health nursing
- Family planning clinics
- STI/STD clinics
- Alaska Native corporations
- Native Hawaiian health organizations
- IHS, tribal, or urban Indian health clinics and hospitals
- Inter tribal councils and organizations
- Indian health boards
- Two spirit societies
- Native drug treatment and wellness programs

### **State Data**

All state health departments have programs designed to conduct local surveillance, process and share data with their own constituents as well as the federal government. Each state produces reports on the state of HIV and AIDS within their jurisdiction, and these are almost always accessible through the respective state's health department website. The quality of data on local Native populations and data indicators collected will vary from state to state. Other sources for state specific data are the Kaiser Family Foundation (for information on a variety of health concerns) and the U.S. Census (for general demographic information)

### **Local Data**

Local data (information on specific cities, town, or counties) can be more difficult to come by as many local organizations do not have an infrastructure or internal expertise that would allow for large amounts of data collection, storage, analysis or distribution. But when it can be located, it is invaluable. Securing these data may take more than just placing a request – it may take time to meet with the organization,

explain your request and then perhaps even sign a memorandum of agreement (or data sharing agreement) that outlines the roles and responsibilities of each party in handling and using the data. Below are some groups that may provide useful information.

- County Health Rankings([www.countyhealthrankings.org/](http://www.countyhealthrankings.org/)) is a site published by the University of Wisconsin Population Health Institute and the Robert Wood Johnson Foundation, which allows you to access data specific to nearly every county in the U.S. It provides percentages, comparisons and rankings to other counties in the state on social and economic factors, clinical care, health behaviors, physical environment, morbidity and mortality.
- Local or county health departments should be capturing data on various governmental programs and these data should be made accessible to the public
- Police or sheriffs' departments can provide local arrest data
- Drug treatment programs may share data on patient intake, demographics and trends.
- Local HIV and AIDS service organizations or programs should have process and outcome data on their own local programs – including testing and intervention programs



**“Hawai’i Nei” by Bernice Akamine**



## “Hawai’i Nei” by Bernice Akamine (Native Hawaiian)

“ ‘*Hawai’i Nei*,’ – Beloved Hawai’i – is laid out on a grid representing the eight cardinal points the Hawaiian navigator used in ancient times to reach Hawaii and the navigator of today currently use to sail the Pacific Ocean. *Hoku pa’a*, Polaris or the North Star, serves as a beacon to guide the navigator back home to the islands.

“Earth pigments are used to color the islands, representing *Papa*, Earth Mother, and our *kuleana*, responsibility and gift, of caring for the land and in return receiving her bounty. Except for the islands of Kaho‘olawe, which is not occupied and Ni‘ihau, which is privately owned, the islands are dyed with pigments from that specific island. The threads used to stitch the circumference of each island to the background are dyed with *mamaki*, a medicinal plant. While the names of each island is stitched with *noni*, another medicinal plant, dyed threads. The HIV/AIDS text was stitched using *koki‘o* dyed thread, an endemic endangered species, used traditionally to dye fishnets. While the *koki‘o* dyed threads refer to our heritage as fishermen, they also refer to the fragility of life. The ocean is dyed with locally gathered indigo, a naturalized plant species, representing the waves of outside influences and illnesses that have been introduced to Hawaii beginning with the arrival of Captain James Cook in 1778.

“Depending on which agency is reporting the statistics, the total number of Native Hawaiian and Other Pacific Islanders (NHOPI) HIV/AIDS cases ranged from 455 to 851, and the number of NHOPI AIDS death numbers ranged from 236 to 355. I chose to list the lower numbers out of those found online because they were the most current and were presented by an agency of the State of Hawaii. While doing the research for the piece, I found the statistics a bit misleading and difficult to decipher, giving me the feeling that one had to have special insight to understand what the numbers were truly saying.

“ ‘Hawai’i Nei’ relies on the concept of *kaona*, hidden meaning or veiled references, that which is understood by those who have been given the knowledge to decipher the piece, or perhaps, that, which is revealed when a person is ready to accept the burden of knowing, or when it is essential for that person to know.”

Media: *kapa*, bark cloth, cotton cloth and threads, and natural dyes

Natural dyes used: ‘*alaea*, *koki‘o*, *mamaki*, *noni*, and indigo.



## BEING A DISCERNING CONSUMER

There are thousands of information sources in dozens of media formats. Whatever our reasons for seeking data, it helps to understand the hows and whys of data collection before we wade into it.

The first step is increasing our level of knowledge. We need to understand some of the areas and concepts that can easily be confused when examining HIV and AIDS surveillance data. This section will address some areas of potential confusion, clarify some misconceptions and explain why some data are presented in certain ways.

The next step is to understand that data alone are nothing more than a set of numbers. It is up to us as prevention and treatment professionals to poke and prod more to fully understand what the data can potentially tell us. There is always more involved than just looking at a chart or reading an article.

### HIV and AIDS Data

Epidemiology reports generally contain information on both HIV and on AIDS. This can be confusing for some consumers, as these data represent two very different facets of the epidemic. It is important to remember that HIV is the virus that infects a person's body and ultimately, over time, leads to the disease known as AIDS. A person can live with HIV for many, many years before receiving an AIDS diagnosis from a doctor. An AIDS diagnosis generally comes when a person's CD4 (a particular white blood cell) count falls below a certain number (usually 200/mL) or level (less than 14 percent of all lymphocytes in the body), or when they have been diagnosed with some of the infections more common to severely immune compromised people (CDC, 1992). So data presented on people living with HIV and people living with AIDS will tell two different stories.

Common data points on HIV include:

- HIV diagnosis or new HIV infection – reports on the number of people receiving a positive (reactive) HIV test for the first time
- People living with HIV (or a diagnosis of HIV infection) – reports on the number of people who have been diagnosed with HIV, but have

yet to progress to an AIDS diagnosis

- Survival time after a diagnosis of an HIV infection - reports on the time that passes between when a person was diagnosed with HIV and when the person passed on (not an indicator that they died from anything related to HIV)

HIV diagnosis data usually help indicate populations at greater risk for acquiring or transmitting HIV, and can indicate the impact of collective risk reduction, prevention actions and testing efforts.

Common data points on AIDS include:

- AIDS diagnoses or new AIDS diagnosis - reports on the number of people whose HIV disease has progressed to AIDS (see above criteria) based on consultation and diagnosis from a doctor
- Persons living with AIDS (or with a diagnosis of an AIDS infection) - reports on the number of people who have been diagnosed with AIDS
- Deaths of persons living with AIDS (or with a diagnosis of an AIDS infection) – reports on those who have had an official diagnosis of AIDS and have already passed on (not an indicator of whether they actually passed away from AIDS related complications)
- Survival time after a diagnosis of an AIDS infection – reports on the time that passes between when a person was diagnosed with AIDS and when the person passed on.
- Time from an HIV diagnosis to an AIDS diagnosis – reports on how long it took for a person to progress from an HIV diagnosis to an AIDS diagnosis

AIDS diagnosis data usually help indicate how and when people are accessing, and using care and treatment, as well as risk populations.

Keep in mind that people living with an AIDS diagnosis have already been diagnosed with HIV as well. So these statistics will include all of the data on people living with HIV. But you can be living with HIV and not have an AIDS diagnosis, so the data on

people living with HIV, does not include people with an AIDS diagnosis; and people living with both HIV and AIDS in their bodies contribute to a population's total community viral load (see page 32 for a description of this concept).

### **Transmission Categories**

The majority of HIV/AIDS surveillance reports published at the national, tribal, state and local levels generally break out the data in a similar fashion – by demographic categories (gender, race/ethnicity and age) and then by transmission categories.

Transmission categories are a very important component of HIV data to understand. This is the classification of a case that indicates the risk behaviors most likely to have been responsible for transmission (CDC, internet surveillance basics). It should be noted that transmission categories are behaviors and are not specific to any identity or person (although it may appear that way).

HIV transmission information is collected at the time of testing and the only way of collecting this information is by asking the person receiving the test. All of the transmission data are based on self-reported information. This makes it less than accurate, since people may not feel comfortable reporting a certain behavior – especially if that behavior is illegal.

- **Male to Male Sexual Contact (MSM)** – The majority of cases among American Indian, Alaska Native and Native Hawaiian people reside among those men who have self identified as having sex with other men. This transmission category label is for men who have had sex with men and attribute this behavior to how they acquired the virus. It may also be abbreviated as MSM (and referred to as men who have sex with men). It is important to note that this is not gay-identified men or two spirit men; rather this label is focused solely on the sexual behavior and not the sexual orientation or gender identity of the men – so it includes gay men, bisexual men and men who are still exploring or experimenting with their sexual identity. As this label only describes men, it will not be associated with women or their statistics.

- **Injection Drug Use (IDU)** – This label is often used to describe injection drug users or the drug culture, but in this case it refers to people who are believed to have acquired HIV through their injection drug use (injecting drugs such as methamphetamine, heroin, steroids, hormones into their bodies using a needle and syringe). This statistic is used to describe the epidemic for both men and women.
- **Male to Male Sexual Contact / Injection Drug Use (MSM/IDU)** – This label often confuses people. This label is used to identify men who have self-identified as both having had sex with men and injected drugs. There is no way for the person or the clinician to know for sure what led to transmission. In this case, clinicians cannot accurately attribute the acquisition of HIV to one behavior or the other, so this label was created to describe the ambiguity. As this label only describes men, it is not associated with women or their statistics.
- **Heterosexual Contact**– This transmission category describes the sexual contact that has taken place between a man and a woman that led to the transmission of the virus. The majority of cases among Native women are a result of heterosexual sexual contact. This statistic is used to describe the epidemic amongst both men and women.
- **Other** – This is a catch all title that is used to report back data that actually fall under several different categories. “Other” will report on people who acquired HIV through the following means:
  - **Hemophilia/coagulation disorder and blood, blood component, or transplant recipient** – These are two separate labels, however, they involve basically the same behavior – people who receive blood products or are exposed as part of a medical procedure. Transmission of HIV through transfusion of contaminated blood or blood components was

first documented in the U.S. in 1982 (CDC, 1982). People who are living with hemophilia or a blood clotting disorder frequently require blood transfusions as a result of the disease. Early on in the epidemic, many hemophiliacs acquired HIV through these transfusions. As a result of mandatory blood screening measures now in place in the U.S., this method of transmission has been all but eliminated. Statistics from early in on the epidemic (1980s – early 1990s) will include more data on hemophiliacs, but it is rare in contemporary surveillance reports.

However, with the passage of laws mandating screening of donated blood products, the use of questionnaires to exclude donors at higher risk for HIV infection, the risk for transfusion-transmitted HIV infection has been almost eliminated in the U.S. (CDC, 2010).

- No Risk Factor Reported or Identified – This category label is designed to represent people who do not know or do not report any risk behavior that could've led to HIV acquisition. It is important to note that this label is generic and simply reflects a group of people clinicians cannot pinpoint a transmission method for. For example, a person who does not feel comfortable disclosing high risk behavior to a clinician may deny having engaged in any high risk behavior at all. It also encompasses groups of people for whom this information may not even have been collected. There are many reasons why the information may not be captured in the data. Clinicians can sometimes make mistakes or may forget to ask questions. They may also feel uncomfortable asking intimate questions; or, they may have been taught that it is disrespectful to ask

about sex or intimate details of certain members of their communities. The cases that fall under this category are generally investigated further by local health department officials to see if a risk behavior or transmission route can be pinpointed. There are other cases in persons whose risk-factor information is missing because they died, declined to be interviewed or were lost to follow-up (CDC, 2011). It should be said that sometimes, depending on the reporting structure or jurisdiction, this category may stand by itself in addition to of the “Other” category.

- Occupational exposures – This label is for people who have been exposed and acquired HIV as a result of their job. For example, doctors and nurses are regularly exposed to the blood of people they serve. This could mean that through an accident or poor adherence to universal precautions a medical professional could be exposed to HIV. This is still pretty rare, but when it does occur and can be identified, data on occupational exposures are captured under the “Other” transmission category as well (Irene Hall, personal communication, 2012).

There are some issues with these transmission category labels. For example, there is not a transmission category for people who report both high risk heterosexual sexual contact and injection drug use. This is because an HIV diagnosis for a person with this behavioral combination would be captured as either heterosexual contact or IDU based on CDC statistical formulas that determine which is “most likely.” This method determines what is plausible even if it's not certain (CDC, 2012a). There is only one combined group for men who have both sex with men and inject drugs, as it is unclear what the more likely route is (Irene Hall, personal communication, 2012).

Also note there are no data on female to female HIV transmission. There are, to date, no confirmed cases

of HIV being transmitted through female to female sexual contact. There have been lesbian, bisexual and two-spirit women that have contracted HIV, but clinicians and disease investigation specialists have attributed the transmission to other higher risk behaviors, such as injection drug use or unprotected heterosexual contact (CDC, 2006).

Note: please check with your tribal health department, tribal/IHS/urban clinic, or state to know how they classify transmission categories, as there can be some variations.

### **Prevalence v. Incidence**

These two key terms describe the impact and spread of HIV and AIDS over time. However, they are frequently confused and used incorrectly.

Prevalence refers to the number cases among a given population. This is simply the number of people who are living with either HIV or with AIDS. However, incidence refers to the frequency of new cases of either HIV or AIDS that occur in a given population during a specific time frame (Dicker and Coronado, 2006).

If a report is talking about AIDS incidence, it is making a statement about the number of people who have progressed from HIV to AIDS (and are newly diagnosed by a doctor as having AIDS). Incidence will always have a time frame attached to it.

Incidence data (especially national level reports) use statistical calculations to determine the most likely time a person was infected with HIV, or the most likely time a person progressed to AIDS, so the case can be most accurately reported within that given timeframe. This is to account for delays in reporting and attempt to be as accurate as possible.

It is important to understand the difference between these two pieces of data. Examining HIV incidence data can serve as indicators of the number of people who are accessing testing services or the success of expanded testing efforts. However, it is very easy to think HIV incidence is a reflection of the number of people who are engaging in high risk behaviors. This is not always the case, and we would need more information to understand what is behind low or high incidence numbers.

HIV prevalence has been on the rise through the years. This makes logical sense because with more new HIV diagnoses each year (incidence), this creates a larger and larger body of people living with HIV. At this time, all people living with HIV will eventually progress to AIDS, and this contributes to the growing AIDS prevalence numbers. As more and more people are accessing HIV medications and are living longer, this also contributes to the consistently rising numbers of both HIV and AIDS prevalence.

Incidence data are often shared as a rate. A rate is a proportion calculated as the number of new HIV cases divided by the size of the population. This statistic is important because it shows the relative impact of the epidemic on populations of varying size. When smaller populations (like the American Indian, Alaska Native, or Native Hawaiian population) have rates higher than those of larger populations, it points to a health disparity. For example, Native Hawaiian and Other Pacific Islanders (NHOPI) have the third highest rate of new HIV infections annually, but make up less than 1 percent of the country's population, whereas the White population has the fifth highest rate of new HIV infections and has the largest population in the country. This doesn't explain why the disparity exists, but simply acknowledges it might be worth exploring further.

AIDS and HIV rates are usually shown in proportion to 100,000 people. For example, the CDC reported in 2010 the rate of new HIV diagnoses among American Indian and Alaska Native (AI/AN) men in 46 states was 18.1 per 100,000 people. This means that for every 100,000 AI/AN men who live in those 46 states, 18.1 of them would have been diagnosed with HIV during 2010.

Prevalence rates are similar in that they also tend to use a 100,000 marker, but of course refer to the existence of the condition rather than new cases. For example, the CDC reported that in 2009, the AIDS prevalence rate for AI/AN people in the state of South Dakota was 52.3 per 100,000. This means that for every 100,000 American Indian or Alaska Native person living in the state of South Dakota, approximately 52 will be living with AIDS.

## **Mortality and Morbidity**

These two terms often appear together in print, but are rarely ever defined, so are often confused with each other. Morbidity refers to the state of sickness or disease in an individual or at the community level. While mortality refers to a fatal outcome (or death). An easy way to think about this is that the numbers, statistics, research and reports released on diagnoses, people living with HIV or AIDS, risk behaviors, transmission categories, etc. all refer to the morbidity of HIV/AIDS. They are all talking about the state of the disease among a living population. Mortality represents all data on deaths associated with HIV or AIDS.

Now there are variations on these terms, of course. Comorbidity is a term used to describe the presence of one or more diseases in addition to a primary disease. For example, if a person living with HIV (the primary disease) is also diagnosed with Hepatitis C, this would be referred to as comorbidity. If the primary disease creates or leads to the presence of another disease, that is called complicated comorbidity. Comorbidity is important to know and explore, as the health of a person living with one disease is often directly impacted by the presence of another disease – which is the case with Hepatitis C and HIV.

## **Community Viral Load**

Viral load refers to number of viral copies of HIV actually in a person's body. This is usually measured by examining a small amount of blood and estimating how many viral copies are in that sample. Viral load is reported as copies per milliliter of blood (copies/mL). Doctors order a viral load test in order to monitor how a person's body is doing fending off the virus and can consequently guide treatment decisions. A high viral load is anywhere from 5,000 to 10,000 copies/mL and a low viral load can be between 40 to 500 copies/mL. A low viral load indicates HIV is not actively reproducing and that the disease is not progressing, whereas a high viral load indicates HIV is extremely active and overpowering the body's natural defenses. It is during these times doctors usually talk about starting or changing HIV treatment regimens to keep the virus at bay. Antiretroviral therapy (ART) lowers a person's viral load. Doctors will regularly test blood samples for viral load in

order to monitor the status of the disease and guide treatment decisions.

Recent research has demonstrated that a person with a high viral load has an increased chance of transmitting the virus, whereas a person with a lower viral load stands a decreased risk of transmission (Donnell, 2010; HPTN, 2011). This research was ground breaking because it led the prevention field to explore two prevention strategies more in depth. The first is to connect people living with HIV to treatment and to ensure that they are adhering to their medication regimen – which is not a new notion. The second is community viral load.

Community viral load (CVL) is a fairly new concept to the surveillance field. Community viral load refers to the level of viral copies within a given population or subpopulation known to be living with HIV. It is taking an individual test (viral load) and applying to a large group of people. Epidemiologists group individual viral load measurements from various groups who have been diagnosed and are receiving HIV care – for example, Native American women, or Latino men who have sex with men. Then, they can compare the average viral load for each of these groups to those of other groups. This comparison allows them to examine health disparities and begin to design strategies to reduce the viral load overall. The thought is if a community can lower its CVL, they will reduce the number of new HIV infections within their group or location.

This has been supported by research – studies have looked at the effect of HIV treatment at the community level. They have demonstrated that as the number of people taking effective HIV treatment has risen, community viral load has decreased, resulting in fewer new HIV infections (Das-Douglas, 2010; Lima, 2008).

For example, a population with a high CVL stands a higher chance of spreading the virus – so prevention measures should be put into place to work with the population as a whole to both lower the viral load through biomedical treatment, and encourage risk reduction behaviors. A population with a high CVL may also show people are being diagnosed very late in the course of their infection, they are not being referred into care early enough, not following

up on referrals provided, or even that they might require additional support or counseling in order to consistently take their meds.

The idea of working within communities with higher viral load is just now emerging. For the longest time, HIV funders and policy makers have been telling organizations to focus on the populations at the highest risk. CVL morphs the concept of “highest risk” into a question of who is living with the virus and who stands the highest risk of transmitting it to somebody else, not who stands the highest risk of getting it from somebody else. Programs and initiatives like the 12 Cities Project and Enhanced Comprehensive HIV Prevention Planning (ECHPP) all recognize the value of increasing prevention efforts in areas and populations with elevated community viral loads.

Using CVL to indicate the effectiveness of HIV antiretroviral treatment and HIV prevention is becoming more popular (Das-Douglas, et al., 2010). Consequently, the federal government, public health decision-makers and the CDC are working to improve the capacity of organizations to be able to monitor this increasingly useful biological measure (Valdiserri, 2011). More reports, articles and data are sure to become available in the future on community viral loads.

### **Comparing Data**

Data rarely stand on their own and should hardly ever be taken at face value. Data are meant to be questioned. One of the easiest ways to do that is to compare it to other data sets. Actually, more often than not, data are presented in such a way that they can be compared to another data set or indicator. This helps put information in a context and help the consumer begin to interpret it. It also helps to point out health disparities, gaps in service and potential strengths or areas of improvement. Any time a report states this or that group has the *highest* or *fewest* number of AIDS cases, or that various groups are at increased risk, then some type of comparison has taken place. Reports that break out data by various demographic characteristics (age, race, geographic region, sex/gender, transmission category) allow consumers to compare the information against each of the other groups. Data collected over time and presented across years or months show a comparison.

Any growth, change, shift, increase, decrease or timespan represented is comparison data.

In order to become wise consumers of data, public health practitioners should seek out opportunities to compare data in order to understand their own local state of the epidemic.

*Case Study:* a journal article is released stating a study across three urban Indian health clinics shows 15 percent of the AI/AN men accessing services at these three clinics are living with HIV. The researchers performing and reporting this work appear to be credible, however, in order to fully understand what this represents, a person needs to compare these data. The following comparisons may help to fully understand the statistics presented by this report.

- Comparing this number against the local HIV prevalence rates for AI/AN men in these three cities to see if it is higher, lower, or relatively the same
- Comparing this number against the same statistics at other urban Indian clinics
- Examining the prevalence of HIV in the total patient population to see if this is higher or lower compared to women, or relatively the same
- Examining the testing practices of the clinic to see if they are only testing men
- Examining data on transmission categories and risk populations collected from the clinic to see how these men identify and how they believe they contracted the virus

Certainly, other comparisons can be made in this example.

Data have a story to tell, but it takes further exploration to really uncover what that story is. Being a consumer of a data is a lot like being a journalist – you have to research more, ask more questions, verify and validate everything, and learn the true story.

## **Estimated Data**

Oftentimes, HIV and AIDS surveillance reports (especially those released on the national level) will feature numbers actually based on estimations rather than real reported numbers. You may see tables with columns designated for reported or actual data and then separate columns for estimated figures (sometimes called statistically adjusted figures) – both for the same data point. The CDC explains that estimated data are used to account for the delay in reporting of HIV and AIDS data from the various sources. The reasons for the delays (which could be as long as several years) vary from area to area, however, complex mathematical models are used to predict the potential number (2012a). The CDC recommends using estimated figures when talking about diagnoses, deaths or prevalence, and warns that rates on estimated numbers that are less than 12 are prone to statistical errors (2012a). Consumers should be aware of whether the surveillance data they are using are based upon actual or estimated figures.

## **Examining Corresponding Health and Social Indicators**

Sometimes data and information on HIV and AIDS are simply not available. A grant writer might find him or herself needing to discuss the need for increased HIV prevention efforts on the reservation, but do not have access to reliable HIV/AIDS statistics for a particular reservation; or, a national report does not provide enough information on the local situation to justify local efforts. This is a common situation. In cases like this it is important to understand the value of related health information, especially information that is more accessible at the local level. There are a number of other health conditions that result from behaviors that can spread HIV or point to the potential incidence or prevalence of HIV; they may not state HIV is present and is a problem, but they can highlight the risk factors or social determinants of health that can contribute to HIV transmission, or point out the prevalence of high risk behaviors on a reservation.

### *Sexually Transmitted Infections*

For many reasons, data on sexually transmitted infections (STIs or STDs) are readily available – data on STIs are regularly and routinely captured by Indian Health Service, public health clinics, community health clinics and private practitioners;

laws require the diagnosis of some STIs be reported; STI testing is more routine and common (especially among women); and STI testing carries slightly less stigma than HIV. Since many of the common STIs (like chlamydia and gonorrhea) are transmitted through the same sexual channels as HIV, reviewing this data can indicate unprotected sexual activity is taking place, as well as indicate the success of various testing or awareness efforts.

This is an effective strategy to show the potential presence of HIV (especially in a setting that doesn't offer regular HIV testing, and when there is no current proof HIV is present in the community). The Indian Health Service periodically publishes a comprehensive and easy to read report on the state of STIs in American Indian and Alaska Native communities; this is an excellent resource to access, review and compare STI rates across the country and IHS service regions.

Knowing the STI rates in an area may also indicate the success or challenges of various testing, awareness and outreach efforts, and may create opportunities for service integration or program collaboration (the same can be said of teen pregnancy, Hepatitis C, violence prevention and substance use efforts).

### *Teen Pregnancy*

Very similar to accessing STI data, reviewing rates of teen pregnancy can help point to the fact that unprotected sexual activity is taking place. It is important to note that it won't explain why it is taking place or barriers to accessing resources, simply that young women are getting pregnant.

### *Hepatitis C*

Hepatitis C is most easily transmitted through blood to blood contact that can happen when two or more people share equipment to inject drugs (i.e., syringes, cookers). With the rates of Hepatitis C on the rise in Indian Country, people are using these statistics to examine the presence of injection drug use in their communities – and where injection drug use is taking place, HIV transmission is possible.

### *Drug Treatment*

The number of people entering drug treatment – whether it is inpatient or outpatient, tribally or



privately run – can shed light on a local drug problem and trends in drug use. Not only can drug use lead to an increased chance high risk sexual behavior will take place, it is a high risk behavior in and of itself.

#### *Hospital Services*

Hospitals collect information on who receives their services as well as what services have been provided. This can be valuable information to help create a picture of who is accessing or not accessing what services. Specific data on admissions or visits (especially in the emergency department) for substance use related conditions, sexual assault, partner violence, suicide or sexually transmitted infections can add to the information that could be used to justify HIV prevention or treatment efforts.

#### *Arrest Reports*

There are various criminal activities that take place in a community that indicate high risk sexual activity, or that several risk factors for HIV transmission are present. If you can access the data on local arrests or charges filed from local or tribal law enforcement, then an examination of sexual assault, partner violence, or substance use-related incidents (e.g., driving under the influence, underage drinking or drug possession) data may help to build a case for HIV prevention or treatment efforts.

#### *Substance Use Data*

There are a lot of data available on mental health, substance use and the prevalence of substance use among Native Americans (American Indians, Alaska Natives and Native Hawaiians), as well as other races and ethnicities. Some of the more common data channels include the Youth Risk Behavior Survey (YRBS) which is administered among school-age youth and reports information on alcohol and substance use, suicide, sexual activity, abuse and risk and protective factors. Other national resources include the reports put out by the National Surveys on Drug Use and Health, National Survey of Substance Abuse Treatment Services, National Institute of Mental Health (NIMH) and the National Institute on Drug Abuse (NIDA).

#### *Demographic Information*

It has been well documented that educational attainment, income level, employment status and homelessness are all either directly or indirectly

associated with HIV infection (Denning and DiNenno, 2010). For example, heterosexual men and women in 23 major U.S. cities living below the poverty line were twice as likely to have HIV infection as those living above it (Denning and DiNenno, 2010), and HIV-infected persons with low reading levels had less general knowledge of their disease and were less likely to follow their medication regimen than those with higher literacy (Osborn, Paasche-Orlow, Rintamaki, Davis and Wolf, 2007; Waite, Paasche-Orlow, Rintamaki, Davis and Wolf, 2008). This kind of data is available through a variety of sources and one of the best places to begin a search of this nature would be the National Library of Medicine.

Don't forget that HIV data (especially state and national data) are always broken out by age and sex. So cases can be made that HIV is impacting one age or racial/ethnic group differently than another. So comparing the national data with local data may help to justify targeting or prioritizing prevention and treatment efforts with one group over another. General demographic information can be located through the national census website.

#### *GBTS Men*

HIV in American Indian, Alaska Native and Native Hawaiian communities continues to disproportionately impact gay, bisexual and two spirit men (GBTS) with the vast majority of new HIV infections and current HIV cases being among this group (CDC, 2012). So it stands to reason that a community with a large or active GBTS population would want to ensure there are testing, prevention and treatment efforts in place to meet their needs. Admittedly, it may be difficult to obtain information on the number of GBTS men living or socializing within a given area (especially rural, frontier, island, or reservation-based areas), but you can research census data on the GBTS community (<http://www.lgbt2012census.com/> or <http://ourfamiliescount.org/census-bureau/>), talk to local two spirit societies, or speak to local gay and lesbian chambers of commerce to get a handle on the size of the community.

#### **Quantitative v. Qualitative Data**

In general, there are two kinds of data – quantitative and qualitative. Both serve distinct purposes in research, and both can provide very different pieces

of a puzzle to anyone seeking to learn more about an issue.

**Quantitative data** is information expressed as numbers. They are the result of carefully designed, objective research projects that use tools such as surveys and questionnaires to classify features, count them and construct statistical models. “Yes or No” questions, questions that you ask you to score or rate something (e.g., on a scale of 1-10), or multiple choice questions are all examples of quantitative data gathering methods. All of this is in an attempt to explain an issue or phenomenon. Quantitatively based projects produce data in the form of numbers and statistics.

Quantitative research and data have a strong presence in the HIV field. In the United States, HIV and AIDS surveillance data are based solely on quantitative methods. Data such as numbers of tests conducted, number of people living with HIV or AIDS, number of new HIV or AIDS diagnoses, are all collected through forms submitted from clinics and medical providers, and form the backbone of surveillance reports generated by agencies like the CDC. The results are countless tables and charts detailing numbers, rates and statistics. Most governmental reports will use quantitative data to present an issue or topic. It is also important to note these data don’t answer the question, “Why?”; they don’t explore the context of any issue. That is left up to qualitative data.

**Qualitative data** are difficult to measure, count, or express in numerical terms. Gathering qualitative data may involve observation, interviewing, and document review.

Qualitative data are the result of research using tools such as discussion groups, observations, focus groups or in-depth interviews. The aim is to completely explore a topic, issue or phenomenon, and create a complete and detailed description or theory. At the end, all data are in the form of words, objects or pictures, and are rich in detail and description.

Qualitative research in HIV is commonly used to explore perceptions, feelings, reactions, norms and attitudes about behaviors, resources, local action and programs. Qualitative methods are common in HIV work during the early stages of a program, when the focus is on understanding a problem fully

so programs can be tailored to address it. They can also be used during program evaluation to understand impact, and during community assessment to gauge community attitudes.

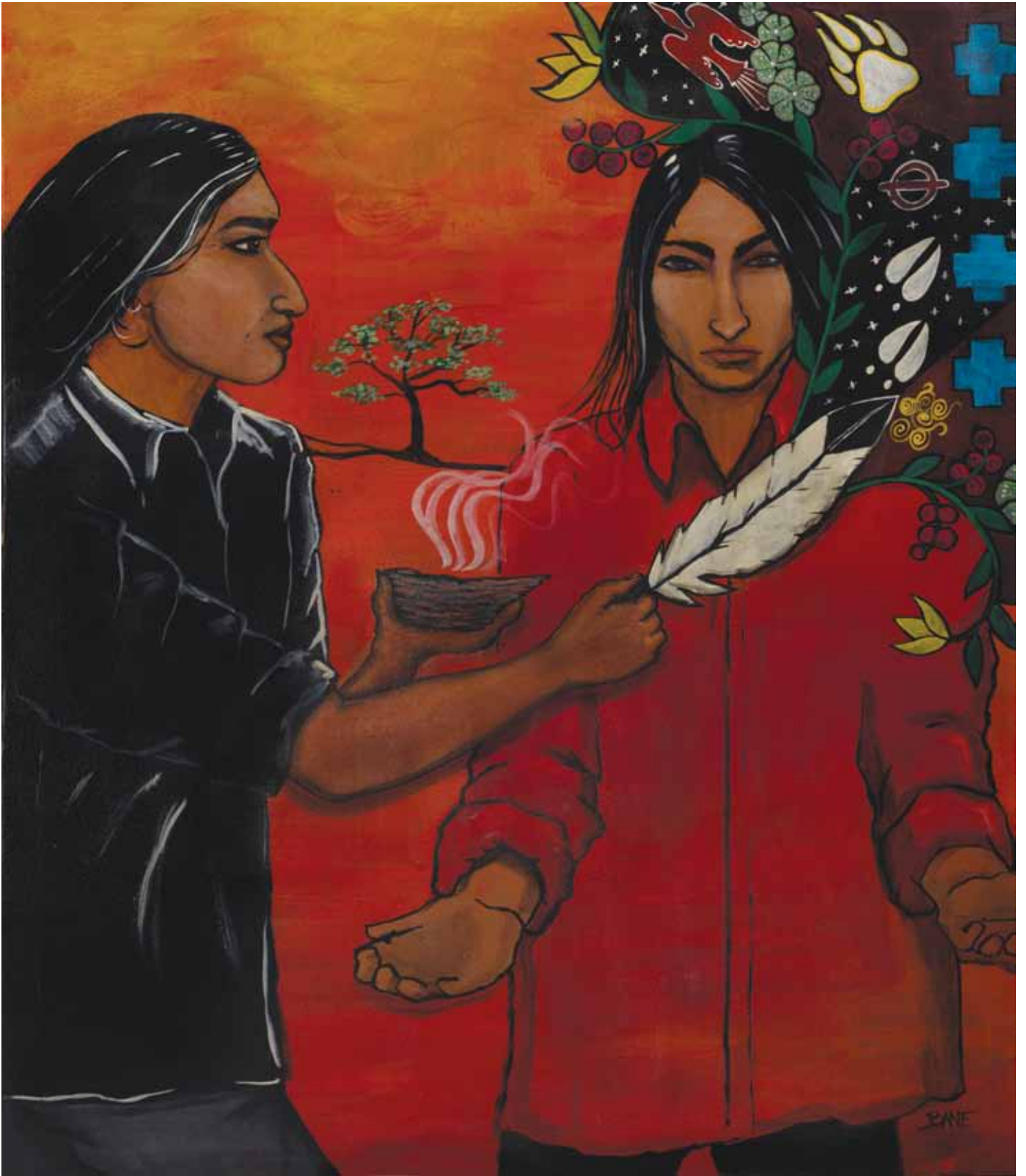
It may appear these two forms of data compete, when in reality, they complement each other wonderfully. For example, a chart in a surveillance report clearly shows very few Alaska Native people are receiving an HIV test at the health clinic in their village, but nobody will know why that is until they start asking people in the village (through interviews and focus groups).

Using both types of data can also help communicate information more effectively. The Center for Prevention & Wellness at Salish Kootenai College (SKC) uses a combination of qualitative and quantitative data because numbers don’t necessarily tell the whole story, and people connect with the messages better when they hear it in a more personal way. Instead of emphasizing percentages and morbidity rates, for example, they craft their social marketing messages on posters or in event promotions to express how HIV might affect their lives and how testing can help them protect themselves.

When wading through the vast amounts of data available, consumers need to be sure to access both quantitative and qualitative information. Don’t just look at the charts and the tables presented in annual reports, but read through the journal articles that speak about the major themes identified in a series of focus groups conducted with reservation-based youth, for instance. Consumers need to examine their own community and not interpret what is happening to youth in California as what is happening to youth in North Carolina (especially since qualitative data are not meant to be generalized like that). However, in the end, understanding the value of using both will paint a more accurate and thorough depiction of the HIV epidemic on any scale.

*Examples Of Qualitative Data Collection Methods:*

- **Literature reviews:** researching what others have discovered about the topic of interest.
- **Focus groups:** 8-12 people with a common characteristic of interest to the project; questions are designed to get to perceptions, attitudes, community norms, etc.
- **Community interviews:** interviews with community members designed to identify information that might not be commonly known about a specific topic.
- **Key informant interviews:** interviews with community leaders or elders that have special knowledge or experience; these interviews provide information about how best to work with a community.
- **Observation:** monitoring an event, presentation, or workshop with intent to provide useful insight into the quality of the event.
- **Games:** these provide an active/interactive method for obtaining information about the usefulness of information delivered and how well skills were developed.
- **Storytelling:** using a traditional Native practice to assess how well an audience understands training content; for example, making up different endings and asking participants to choose, or having participants make up their own story and ending (role-plays).
- **Talking Circles:** a confidential way of finding out how different individuals think or feel about a certain situation.
- **Case studies:** these provide a means for role-play and observation to model desired behavior.



“Untitled” by Alistair Andrew Bane

## “Untitled” by Alistair Andrew Bane (Shawnee)

“I was very happy to have a chance to create this painting for NNAAPC. I wanted this painting to talk about healing and strength. I was a teenager when the AIDS epidemic began. Since then, I have seen many people work in many different ways to help our community in our battle against HIV and AIDS – there are doctors, prevention outreach workers, case managers, and more, all of who do important work. In this painting I chose to talk about the healing and strength that we receive through our traditional ways.

“In the painting, the figure on the left is doctoring the figure on the right with an eagle feather and cedar. The figure on the right wears a red shirt. Red is the color of strength as well as the color often used to represent persons living with HIV/AIDS. The figure who is being doctoring is surrounded by images that represent some of our different medicine ways. Our Nations all have their own unique ceremonies and ways of doctoring – all of which are beautiful.

“All of our community has been affected by HIV/AIDS; however, when I painted this piece I was thinking of two spirit people in particular. In our ways, we value every member of our community, but having grown up in a city, I saw that oftentimes the outside world gives two spirit people a very negative message about themselves. Although great strides have been made, I still meet many young people who feel alone in this world or are told that they are not valued. Our health is a combination of our mind, body and spirit, and it is important for every human being to feel loved, valued and cared for in order to be well. My hope is that this painting expresses the connection and love that gives our communities their strength. Maybe if someone looks at this painting when they are feeling alone, they can be reminded they are loved and valued, not only by us who are here now, but all those ancestors who watch over us.”

## CULTURAL WAYS OF COMMUNICATING DATA

If our communities truly want to use and communicate data about our own populations, part of the process should reflect our specific cultures. Using traditional symbols, images and narratives help to connect people to the data in a non-linear way, but these things are just the beginnings of communication. We share information through art, stories and ceremonies, and often use concepts that may not have a corresponding term in American English.

One example is the artwork of Bernice Akamine:

“‘Hawai‘i Nei’ relies on the concept of *kaona*, hidden meaning or veiled references, that which is understood by those who have been given the knowledge to decipher the piece, or

perhaps, that, which is revealed when a person is ready to accept the burden of knowing, or when it is essential for that person to know.”

*Kaona* involves readiness to accept information, and shows respect for the process of giving information to others. As public health professionals working in Native communities, we are often called upon to decipher information and share it with tribal leaders, clients, co-workers, as well as friends and family. Additionally, there are many others who take on the roles of teachers, wisdom keepers, speakers and advisers.





HIV and AIDS can be difficult to talk about because the subjects of sex, drugs, sickness and death are often considered impolite or even taboo in many situations. Many of our communities also have stigmas around related subjects such as being gay, teen sex, injection drug use, etc. These are personal issues, and many of our cultures value privacy and not getting involved in the affairs of others. Information also has a time and a place, and public health data is important information, especially for those who are at personal risk and those who make decisions for the community.

We often look to elders or those who have particular kinds of knowledge to share. In the case of HIV, groups of individuals who take on the role, or have gained the respect and standing, are prepared to educate community members on sensitive subjects. Some are members of sacred clown societies, kachinas or similar groups; other individuals, like comedians and youth role models, can speak to these topics with teaching stories, humor, songs and skits that can raise our awareness and bring the messages home. Elders also communicate this kind of information during coming-of-age ceremonies or at other appropriate times, according to tradition.

Many among us who live with HIV/AIDS feel called to become speakers and presenters at health and HIV/STD awareness events. Native women and men like Shana Cozad (Kiowa/Caddo/Delaware) and Isadore Boni (San Carlos Apache) carry the experience, the knowledge and the strength to talk about the issues. Their stories reach people with the reality of the virus and the risks, and inspire us with their courage to lead the fight against the spread of HIV in Indian Country.

Another successful way to reach out has been through student leadership. Several Tribal colleges have student groups and activities that are LGBTQTS-inclusive and proactive in bringing awareness to issues surrounding sexual health and the factors leading to drug use. In Montana, for instance, Spirit of Many Colors (SOMC), the Gay-Straight Alliance of Salish Kootenai College,

provides a setting of celebration, support and open discussion for all students regardless of sexual orientation or gender identity. SOMC currently hosts bi-weekly meetings, fundraisers and PRIDE events. SKC is the first Tribal college to host a PRIDE week.

Messages of how HIV spreads, how it can affect our tribes and how we can support those whose lives have been changed forever by HIV, need our words, our thoughts and our people to communicate them effectively.

## APPLICATIONS OF DATA

### Community Strengths

Each of the 560+ Native tribes in the U.S. has its own unique social norms and customs. Each also has community-level differences in acculturation and traditional practices. Research in the field of Native caregiving identifies key concepts that cross Native cultures. These key concepts are caring, tradition, respect, connection, holism, trust and spirituality. These concepts are qualities that can be integrated in how epi data is used in particular communities.

Our communities also have a lot in their favor when addressing HIV and AIDS:

- Experience with epidemics – our current response to HIV and AIDS is based in other experiences with diseases like typhoid fever and small pox, and is closely related to gonorrhea, Chlamydia and HCV.

- Different view of pathology in an individual and the community – the Native view of sickness is often related to an imbalance in the life of the individual or the community. And instead of viewing a short-term cure, this view usually addresses the long-term needs in many aspects of life: mental, physical, emotional and spiritual.
- Relationship with family and community – as part of this holistic view, we reach out to extended family and community for support in ceremonies, resources and counseling.
- Understanding of traditional medicines – in addition to medical and pharmaceutical approaches to prevention, treatment and care, there are many medicines that can help alleviate difficult side effects and promote overall wellness.
- Prayer and ceremony – connecting with elders and community through ceremonies and prayer can often help Natives understand their own risk behaviors and offer a path to wellness.
- Beliefs in overall wellness and balance

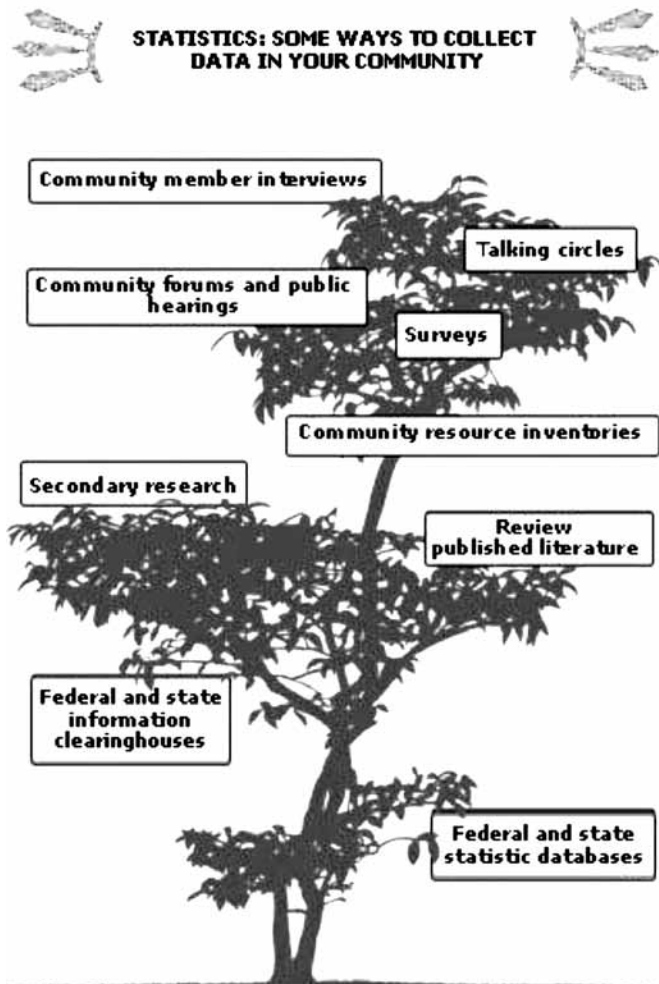


Chart 1 - When starting the process of gathering and using local data, it is helpful to begin with a list of specific questions to help determine the best method of data collection for your program.

For example:

- What kind of demographic information (age, race, etc.) do you need to know?
- What types of behaviors are you curious about?
- Will your community be sensitive about answering personal questions in a group?
- Do you need to know about current use of services?
- Do you need to know about current behaviors?
- What about the impact of the program or intervention on behavior?



We can make use of these strengths to look at the challenges we face locally and own the response. If we reframe the data and analyze them within our respective cultures, the question of disease prevention will look very different. For instance, data on the national level often shows health disparities or inequities in health care services for Natives. Our communities often have high rates of diabetes, cancer, etc., and low levels of health education and poor access to basic health care. Not all our communities face these nationally-identified challenges. But, even if those numbers do reflect local realities, we can still address the problems in terms of what we want or need for ourselves, and not what we need in comparison to other groups, or more importantly, what others want for us.

One example is the Inter Tribal Council of Arizona, Inc. (ITCA). They work with 20 tribes on health issues such as diabetes and HIV/AIDS with the strengths of each community. Their mission is “to be the voice of the member Tribes in bringing about

Indian involvement and self-determination,” and is reflected in how they use data to address their health needs. The ITCA emphasizes wellness in the community. This strengths-based approach is proving successful with not only disease, but the idea of health and well-being overall. (See page 44)

### Collecting Local Data

We may have the tools to combat HIV and AIDS, but we don’t always have enough local data to tell us what is going on. It is to our advantage to gather and keep our own data, in addition to state and national data, to inform our response: developing programs, seeking the right kind of funding, identifying possible collaborations, etc. In this next section, we will talk about those Native-specific and/or tribally based responses.

As Native people we traditionally take a holistic approach to health and wellness. According to this view, health equates to the harmony of body and soul with nature. Illness implies an imbalance

**Table 2 - Response Frequencies Received in Client Satisfaction Survey Regarding Ahalaya Case Management Services (n=130)<sup>1</sup>**

SPECIFIC RESPONSE CATEGORIES	PERCENTAGE RESPONDING
Felt they experienced reductions in stress	78.9
Felt they experienced reductions in alcohol consumption	67.9
Felt they experienced reductions in drug use	74.4
Felt they experienced reductions in sadness	83.1
Felt they received assistance when dealing with families	73.1
Felt they received assistance in finding a home	60.5
Felt they received assistance making appointments	82.3
Felt they received assistance in getting medications	79.1
Liked the AI/AN/NH affiliation of these projects	92.3
Thought the programs were better by Native affiliation	83.1
Liked having access to traditional healers	65.9
Liked having access to support groups	76.4
Learned about prevention strategies	86.9
Expressed an interest in learning more about prevention strategies	61.5
GENERAL RESPONSE CATEGORIES	PERCENTAGE RESPONDING
Were glad to have received these services	93.2
Had been helped by these programs	92.2
Believed the Ahalaya Program made their lives better	87.7

<sup>1</sup>Bouey, P.D., & Duran, B.E. (2000). The Ahalaya Case-Management Program for HIV-Infected American Indians, Alaska Natives and Native Hawaiians: Quantitative Evaluation of Impacts. *American Indian Alaska Native Mental Health Research*, 9(2): 36-52.

within the individual and between the individual and the universe. As noted in the following case study, Native patients who access traditional medicine and ceremonies report physical relief as well as an overall increase in their sense of well-being. This type of data might be difficult to track by gathering only quantitative data. To document cultural strengths and values, always keep a holistic viewpoint in mind when gathering health and wellness information in your community. This will help you to gather information to develop an HIV/AIDS program rooted in Native values.

**Program Planning** – Epi data is valuable to health care programs to gauge community priorities or needs, encourage growth or momentum for programs, build new partnerships, and prioritize/allocate resources.

*Case Study: Ahalaya Case Management Model*  
Ahalaya was originally a program developed to address the needs of HIV+ two spirit individuals in Oklahoma. It was eventually implemented in several locations for Native Hawaiians, Alaska Natives and American Indians. The program was created by Natives for Natives, and integrates traditional and spiritual practices into a client-centered, holistic health care plan. After the initial project was completed, a client opinion survey was conducted, focusing on quality of services and program activities. The results demonstrate positive health outcomes and attitudes toward Ahalaya care. In this case, several sets of local qualitative data (opinions and attitudes) were put together to form a picture of what the program overall achieved. (See Table 2, page 43)

Additionally, state and regional epi data from organizations such as the Oklahoma University Medical Center and the Oklahoma City Area Inter Tribal Health Board helped identify program recruitment and services locations, as well as tribal resources.

**Monitoring and Evaluation** – process and outcome evaluation, program planning through logic modeling, demonstrating program effectiveness

*Case Study: Inter Tribal Council of Arizona, Inc. (ITCA) Tribal Epidemiology Center*

The Inter Tribal Council of Arizona, Inc. has 20 member tribes and houses the ITCA Tribal Epidemiology Center, which serves the tribes in the Phoenix Area and Tucson Area of the Indian Health Service. In collaboration with the ITCA Health Promotion Department, the ITCA Tribal Epidemiology Center works closely with members and other tribes in the region to strengthen HIV and related programs through the provision of sound and reliable epidemiological information. They take a two-fold approach to presenting epidemiology data and statistics – one, putting the technical data into common language of each community; and two, creating community-specific cultural messages to highlight issues, as well as using local numbers, descriptive data, ideas on gender roles that may affect HIV risk, and particular responses to HIV as a community.

Even as distinct communities, many tribes share a common goal – a strong belief that “one is too many” for HIV related deaths.

ITCA also uses a tribally-driven approach that requires efforts to be led by tribal leaders, staff and members with vested interests in the programs. They use local data to apply for funding, and to demonstrate a need in their communities. Monitoring and evaluating health outcomes are key in developing new and improving existing programs that address the identified needs of the communities. They help members by creating community health profiles on STDs and diabetes, for example, and by helping tribes develop reports and analyze data. Perhaps the most important question in the monitoring and evaluation process is, “What is our response going to be?”

**Sharing Data Among Tribal Groups** – bridging gaps, building communication and consolidating data streams

*Case Study:* California Tribal Epidemiology Center  
Tribal Epidemiological Centers (TECs) work in partnership with local or area tribes by offering culturally-competent technical support, services and materials. The California Tribal Epidemiological Center, based in Sacramento, strives “to improve American Indian health in California to the highest level by engaging American Indian communities in collecting and interpreting health information to establish health priorities, monitor health status, and develop effective public health services that respect cultural values and traditions of the communities.”

Through data sharing agreements (DSA), CTEC works with tribes to monitor data on local communities. They currently use publicly available data sources, as well as conduct studies linking data to Medicaid/Medicare, cancer surveillance, Indian Health Service and California State Department of Public Health data.

From this data, they develop materials that are geared toward each of their constituent tribal groups. They work to ensure all of their publications reflect the various tribes and cultures in California by using appropriate designs, photography and tribal specific imagery.

They also make all of their reports available online, and when possible print them and mail them to all federally recognized tribes and tribal health programs in their region. A copy of their DSA is available online for reference: [http://crihb.org/files/CTEC\\_Data\\_Sharing\\_Agreement\\_2011.pdf](http://crihb.org/files/CTEC_Data_Sharing_Agreement_2011.pdf)



## RESOURCES

HIV and AIDS Glossary: <http://www.aidsinfo.nih.gov/education-materials/glossary>

Glossary of Epidemiological Terms: <http://www.cdc.gov/excite/library/glossary.htm>

*AIDSVu* provides a high-resolution view of the geography of HIV in the United States, 30 years into the epidemic. It is an online tool that allows users to visually explore the HIV epidemic alongside critical resources such as HIV testing center locations and NIH-Funded HIV Prevention & Vaccine Trials Sites. The data on AIDSVu comes from the U.S. Centers for Disease Control and Prevention's (CDC) national HIV surveillance database that is comprised of HIV surveillance reports from state and local health departments. AIDSVu will be updated on an ongoing basis in conjunction with CDC's annual release of HIV surveillance data, as well as new data and additional information as they become available. <http://aidsvu.org/>

HIV and AIDS Statistics and related information: <http://www.avert.org/statistics.htm>

### Indian Health Boards

Great Plains Tribal Chairmen's Health Board  
1770 Rand Road  
Rapid City, SD 57702  
605-721-1922

Alaska Native Health Board  
1840 Bragaw St. #220  
Anchorage, AK 99508-3463  
907-743-2524

Albuquerque Area Indian Health Board  
5015 Prospect Avenue NE  
Albuquerque, NM 87110  
505-764-0036

Midwest Alliance of Sovereign Tribes  
1011 Main Street  
Gresham, WI 54128  
715-787-4494

Montana-Wyoming Tribal Leaders Council  
222 N. 32nd St., Ste. 401  
Billings, MT 59101  
406-252-2550

California Area Indian Health Board  
4400 Auburn Boulevard, 2nd floor  
Sacramento, CA 95841  
916-929-9761

United Southern and Eastern Tribes, Inc.  
711 Stewarts Ferry Pike Ste. 100  
Nashville, TN 37214  
615-467-1540

Navajo Nation Division of Health  
P.O. Box 1390  
Window Rock, AZ 86515  
928-871-6350

Oklahoma City Area Inter-Tribal Health Board  
701 Market Drive  
Oklahoma City, OK 73114  
405-951-6005

Inter-Tribal Council of Arizona  
2214 N. Central Ave. Suite 100  
Phoenix, AZ 85004  
602-258-4822

Northwest Portland Area Health Board  
2121 SW Broadway, Suite 300  
Portland, OR 97201  
503-228-4185

## **Tribal Epidemiology Centers**

**Alaska Native Tribal Epidemiology Center** –  
Anchorage, AK  
<http://www.anthc.org/chs/epicenter/index.cfm>

**Albuquerque Area Southwest Tribal Epidemiology Center** – Albuquerque <http://www.aastec.net/default.asp?DomName=aastec.net>

**California Tribal Epidemiology Center-**  
Sacramento, CA  
<http://www.crihb.org/home/california-epi-center>

**Great Lakes Tribal Epidemiology Centers** – Lac  
du Flambeau, WI  
<http://www.glitc.org/epicenter/index.html>

**Inter-Tribal Council of Arizona Inc. Epidemiology Center-** Phoenix  
<http://www.itcaonline.com/epi/index.html>

**Rocky Mountain Tribal Epidemiology Center-**  
Billings, MT  
<http://www.rmtec.org>

**Navajo Nation Tribal Epidemiology Center** –  
Window Rock, AZ

**Northern Plains Tribal Epidemiology Center** –  
Rapid City, SD  
<http://www.aatchb.org/nptec/>

**Northwest Tribal Epidemiology Center** – Portland,  
OR  
<http://www.npaihb.org/epicenter>

**Southern Plains Inter-Tribal Epidemiology Center**  
– Oklahoma City  
<http://www.ocaithb.org/>

**United South and Eastern Tribes Tribal Epidemiology Center** – Nashville  
<http://usetinc.org/Programs/USET-THPS/TribalEpiCenter.aspx>

**Urban Indian Health Institute Epidemiology Center** – Seattle  
<http://www.uihi.org/>



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## Notes