National Tribal Forum
For Excellence in Community Health Practice

Beyond Accreditation: Using Data to Improve Community Health

Data Resources

The resources in this handout are focused on data sources for the Portland Area (Idaho, Oregon, and Washington). To learn more about data resources available in your area, contact the Tribal Epidemiology Center (TECs) that serves your area. You can find a full listing of TECs with links to their websites at:

http://tribalepicenters.org/

Where to Access AI/AN Health Data

Northwest Tribal Epidemiology Center

As a part of our technical assistance program to Northwest Tribes, IDEA-NW can provide national and/or local data reports to health professionals. In many cases, these data are more complete and accurate than what is available through the state or national agencies as we have corrected them for racial misclassification through data linkage with the Northwest Tribal Registry. Contact us at ideanw@npaihb.org and we will be happy to assist you with your data needs.

Currently our data catalog includes:

- Birth certificates for Idaho, Oregon and Washington
- Death certificates for Idaho, Oregon and Washington (including multiple cause of death file)
- Hospital Discharge data for Oregon and Washington (includes a wide range of health topics)
- Cancer registry data for Idaho, Oregon and Washington
- Trauma registry data for Washington (most recent 2009)
- Childhood blood lead registry for Oregon (most recent 2010)
- Portland Area GPRA data

Below we have provided a curated list of data sources by topic area you might find useful. This list is not exhaustive but these sources are those most likely to provide current AI/AN specific data at a state level or below. Contacting your county or state health department is also a good place to begin.

General (These sources have data on a wide variety of topics)

Washington Community Health Assessment Tool (CHAT)
Web-based tool to access Washington State Department of Health data. It includes access to vital statistics, hospitalization, demographics, injury, communicable disease and cancer.
Access at
http://www.doh.wa.gov/ForPublicHealthandHealthcareProviders/PublicHealthSystemResourcesandServices/CommunityHealthAssessmentandImprovement/CHAT
Or contact the CHAT coordinator at CHS.CHAT@doh.wa.gov

Summary:

Access?	By request (sign a data use agreement, create an account)
Smallest geographic unit available?	Varies but some down to county
States included?	Washington only
Topic?	Various
Most recent year available?	Kept pretty up to date with the most recently available
Raw data available?	Possibly by request
AI/AN specific data available?	Yes
Corrected for racial misclassification?	No

OR VistaPHw/OR Public Health Assessment Tool (OPHAT)
Web-based tool to access Oregon State public health data. It includes access to vital statistics, hospitalization, demographics, injury, communicable disease and cancer.
Access at: http://ophat.public.health.oregon.gov/Account/LogOn?ReturnUrl=%2f
Or email OPHAT.Administration@state.or.us.
Summary:

Access?	By request (sign a data use agreement, create an account)
Smallest geographic unit available?	Varies but some down to county
States included?	Oregon only
Topic?	Various
Most recent year available?	Kept pretty up to date with the most recently available
Raw data available?	Possibly by request
AI/AN specific data available?	Yes
Corrected for racial misclassification?	No

County Health Rankings

Provides a range of health, social, economic and demographic statistics in one easy tool, by county. It does not provide AI/AN specific data, but could be useful for general overview of county health or comparisons to local data.

Access at: http://www.countyhealthrankings.org/

Summary:

Access?	Public
Smallest geographic unit available?	County
States included?	All
Topic?	Various
Most recent year available?	Varies but most around 2012-2013
Raw data available?	Yes
AI/AN specific data available?	No
Corrected for racial misclassification?	N/A

Indian Health Service EPI Data Mart

IHS collects patient registration records, encounter records and CHS claims and purchase order data from IHS and tribal clinics, and some additional legacy data, which are available for some eligible non-D1 users through the Epi Data Mart. The Northwest Tribal Epicenter has permission to access these data on behalf of Northwest Tribes. Contact us at ideanw@npaihb.org to determine if the Epi Data Mart data may be of use for you.

Summary:

Access?	Restricted
Smallest geographic unit available?	Service Unit or clinic
States included?	All
Topic?	Clinic use and patient health
Most recent year available?	Unknown
Raw data available?	No

National Health Interview Survey (NHIS)

Conducted every few years and has a large sample of about 35,000 households. Questions include a broad range of health and behavior topics. Race data are collected, but only census region level data are available publically. It is possible that smaller geographies could be requested through the CDC "Restricted Data Center"

Access Publically at: http://www.cdc.gov/nchs/nhis.htm - to census region

Access By Request at: http://www.cdc.gov/rdc

Summary:

Access?	Public
Smallest geographic unit available?	Publically census region; possibly census block by request
States included?	All
Topic?	Various
Most recent year available?	2014
Raw data available?	Yes
AI/AN specific data available?	Yes
Corrected for racial misclassification?	No but collected through self-report with multiple race allowed

CDC WONDER

Online database which allows customized queries of birth, death, cancer, TB, STDs, AIDS, population and environmental data. Note that births, deaths, and cancer data are drawn from the same sources that IDEA-NW data come from but are not corrected for racial misclassification; we recommend contacting IDEA-NW for these data if wishing to find the most accurate AI/AN statistics for ID, OR and WA.

Access at: http://wonder.cdc.gov/Welcome.html

Summary:

Access?	Public for most
Smallest geographic unit available?	AIDS diagnoses by census region or MMA; Births by county; Cancer by state or MSA; deaths by state
States included?	All
Topic?	Various
Most recent year available?	2002 for AIDS data; 2013 for births and deaths; 2012 for cancer
Raw data available?	No
AI/AN specific data available?	Yes
Corrected for racial misclassification?	No

Maternal and Child Health, Births

IDEA-NW

The IDEA-NW project at NWTEC conducts regular data linkages with Idaho, Oregon and Washington birth certificate files and retains the complete file for analysis. We create state-level AI/AN birth data fact sheets and can conduct analyses specific to your project.

Access fact sheets at: http://www.npaihb.org/epicenter/project/reports

Request additional analyses at: ideanw@npaihb.org

Summary:

Access?	Fact Sheets publically, other analyses by request
Smallest geographic unit available?	Down to county depending on population size
States included?	Idaho, Oregon and Washington
Topic?	Birth certificate data
Most recent year available?	2012 for Idaho, 2013 for Oregon and Washington
Raw data available?	No
AI/AN specific data available?	Yes
Corrected for racial misclassification?	Yes (only source for this)

March of Dimes Peristats

Web portal compiling maternal and child health data from birth certificate and PRAMS (WA and OR)

Access at: http://www.marchofdimes.org/peristats/Peristats.aspx

Summary:

Access?	Public
Smallest geographic unit available?	County, Seattle and Portland
States included?	Idaho, Oregon and Washington
Topic?	Birth certificate data and some PRAMS data for WA & OR
Most recent year available?	2013
Raw data available?	No
AI/AN specific data available?	For some indicators
Corrected for racial misclassification?	No

Census of Juveniles in Residential Placement

Online tool to access data about juvenile offenders

Access at: http://www.ojjdp.gov/ojstatbb/ezacjrp/

Summary:

Access?	Public
Smallest geographic unit available?	State
States included?	All
Topic?	Child and adolescent health
Most recent year available?	2013
Raw data available?	No
AI/AN specific data available?	For some indicators
Corrected for racial misclassification?	No

National Data Archive on Child Abuse and Neglect (NDACAN)

Access point for several studies of child abuse, neglect and foster care status. Each must be requested directly, unsure if AI/AN data are available for all.

Access at: http://www.ndacan.cornell.edu/datasets/datasets-list.cfm

Summary:

Access?	Public
Smallest geographic unit available?	County, depending on sample size
States included?	All
Topic?	Child abuse and neglect
Most recent year available?	2013
Raw data available?	By request
AI/AN specific data available?	Yes
Corrected for racial misclassification?	No

Kids Count Data Center

Compilation of several data sources but only child and adolescent statistics. Data come from surveys, birth certificates, death certificates, law enforcement, census, NDACAN, etc. Select your geographic area, topic and then scroll down to see what is under "indicators by race/ethnicity"

Access at: http://www.ndacan.cornell.edu/datasets/datasets-list.cfm

Summary:

Access?	Public
Smallest geographic unit available?	Down to county, but only a few AI/AN indicators at county
States included?	All
Topic?	Child and adolescent health, demographics, education, welfare, safety and risk behaviors
Most recent year available?	Varies by data source
Raw data available?	No
AI/AN specific data available?	For some indicators
Corrected for racial misclassification?	No

Drug Use Among Young American Indians: Epidemiology and Prediction

Annual survey of American Indian adolescents (grades 7 -12) attending schools on or near reservations.

Access at: http://doi.org/10.3886/ICPSR35062.v3

Summary:

Access?	Public
Smallest geographic unit available?	Region (Northwest combines ID, OR and WA)
States included?	All
Topic?	Adolescent drug use
Most recent year available?	2013
Raw data available?	Yes
AI/AN specific data available?	Yes
Corrected for racial misclassification?	No but self-report, multiple race selection allowed

Substance Abuse & Mental Health

IDEA-NW

The IDEA-NW project at NWTEC conducts regular data linkages with Idaho, Oregon and Washington death certificate files and retains the complete file for analysis. We have created a regional suicide fact sheet

Access fact sheets at: http://www.npaihb.org/epicenter/project/reports

Request additional analyses at: ideanw@npaihb.org

Summary:

Access?	Fact Sheet publically, other analyses by request
Smallest geographic unit available?	Down to county depending on population size
States included?	Idaho, Oregon and Washington
Topic?	Suicide deaths
Most recent year available?	2012 for Idaho, 2014 for Oregon and Washington
Raw data available?	No
AI/AN specific data available?	Yes
Corrected for racial misclassification?	Yes (only source for this)

National Mental Health Services Survey (N-MHSS)

National survey collecting information on mental health treatment facilities as well as numbers and demographics of people served at those facilities.

Access at: http://doi.org/10.3886/ICPSR34945.v2

Summary:

Access?	Public
Smallest geographic unit available?	State
States included?	All
Topic?	Mental health treatment
Most recent year available?	2010
Raw data available?	Yes (note - each case represents one facility, not one client)
AI/AN specific data available?	Yes
Corrected for racial misclassification?	No

Treatment Episode Data Sets – Admissions and Discharges (TEDS-A and TEDS-D)

National census data system of people admitted to and discharged from substance abuse treatment programs that receive public funding. Variables include demographics, medical history, substance abused, diagnosis codes, insurance status, arrests and treatment history.

Access at: http://doi.org/10.3886/ICPSR35074.v1 (TEDS-D)
http://doi.org/10.3886/ICPSR35037.v1 (TEDS-A)

Summary:

Access?	Public
Smallest geographic unit available?	Core Based Statistical Area (metro and micro areas)
States included?	All
Topic?	Substance Abuse treatment
Most recent year available?	2012 (TEDS-A), 2011 (TEDS-D)
Raw data available?	Yes
AI/AN specific data available?	Yes
Corrected for racial misclassification?	No

Drug Use Among Young American Indians: Epidemiology and Prediction

Annual survey of American Indian adolescents (grades 7 -12) attending schools on or near reservations.

Access at: http://doi.org/10.3886/ICPSR35062.v3

Summary:

Access?	Public
Smallest geographic unit available?	Region (Northwest combines ID, OR and WA)
States included?	All
Topic?	Adolescent drug use
Most recent year available?	2013
Raw data available?	Yes
AI/AN specific data available?	Yes
Corrected for racial misclassification?	No but self-report, multiple race selection allowed

Sexually Transmitted Disease and Communicable Disease

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

Mapping tool to show incidence and prevalence of these STD and communicable diseases

Access at: http://gis.cdc.gov/GRASP/NCHHSTPAtlas/main.html

Summary:

Access?	Public
Smallest geographic unit available?	County for all races, state for AI/AN
States included?	All
Topic?	HIV/AIDs, Viral Hepatitis, STDs and TB
Most recent year available?	2013
Raw data available?	No
AI/AN specific data available?	Yes
Corrected for racial misclassification?	No

IHS STD Surveillance Reports

Static reports updated every two to three years. Note that data come from the National Notifiable Disease Surveillance System which may have high rates of racial misclassification; further note that only AI/AN living in IHS CHSDA counties are included.

Access at: http://www.cdc.gov/std/stats/IHS/default.htm

Summary:

Access?	Public
Smallest geographic unit available?	IHS Area
States included?	All
Topic?	Chlamydia, Gonorrhea, Primary & Secondary Syphilis
Most recent year available?	2011
Raw data available?	No
AI/AN specific data available?	Yes
Corrected for racial misclassification?	No

Injury

IDEA-NW

The IDEA-NW project at NWTEC conducts regular data linkages with Idaho, Oregon and Washington death certificate, trauma registry and hospital discharge files and retains the complete files for analysis.

Access hospital fact sheets and reports at: http://www.npaihb.org/epicenter/project/reports

Request additional analyses at: ideanw@npaihb.org

Summary:

Access?	Fact Sheets and reports, other analyses by request
Smallest geographic unit available?	Down to county depending on population size
States included?	Idaho, Oregon and Washington
Topic?	Injury deaths, trauma cases (WA only), injury hospitalizations (OR and WA only)
Most recent year available?	Deaths & hospitalizations updated annually. Trauma 2009
Raw data available?	No
AI/AN specific data available?	Yes
Corrected for racial misclassification?	Yes (only source for this)

Fatality Analysis Reporting System (FARS)

FARS contains data on fatal motor vehicle crashes in the US that occur on a public roadway and involve a fatality. The web portal allows users to run customized queries. FARS contains details about the crash, vehicle, drivers and occupants, and pre-crash circumstances. Data are extracted from multiple sources. Note – use the variable "special jurisdiction" to access information about crashes on reservations.

Access at: http://www.nhtsa.gov/FARS or for AI/AN specific maps go to http://www-nrd.nhtsa.dot.gov/departments/nrd-30/ncsa/STSI/NA_Report.htm

Summary:

Access?	Public
Smallest geographic unit available?	By reservation or GPS coordinates of crash in some cases
States included?	All
Topic?	Fatal motor vehicle crashes
Most recent year available?	2012 for reservation stats, 2011 for AI/AN specific
Raw data available?	Possibly by request
AI/AN specific data available?	Yes
Corrected for racial misclassification?	No (reports come from a variety of sources, but may be unreliable for driver/occupant race)

Education

National Indian Education Study (NIES)

Performance results from the National Assessment of Educational Progress (NAEP) in reading and mathematics for a sample of AI/AN students. Updated every two years.

Access at: http://nces.ed.gov/nationsreportcard/nies/

Summary:

Access?	Public
Smallest geographic unit available?	State
States included?	Select states; for our region only Oregon and Washington
Topic?	Education
Most recent year available?	2011
Raw data available?	No
AI/AN specific data available?	Yes
Corrected for racial misclassification?	No

Washington State Report Card (Office of Superintendent of Public Instruction)

The state report card includes information about students in Washington schools including graduation rates, standardized testing scores and other performance measures.

Access at: http://reportcard.ospi.k12.wa.us/DataDownload.aspx

Summary:

Access?	Public
Smallest geographic unit available?	By school in some cases, district for others
States included?	Washington
Topic?	Education
Most recent year available?	2015
Raw data available?	Yes
AI/AN specific data available?	Yes
Corrected for racial misclassification?	No

State of Washington Office of Superintendent of Public Instruction Data and Reports page

Includes Statewide Longitudinal Data System, graduation and dropout statistics, and discipline data

Access at: http://www.k12.wa.us/dataadmin/

Summary:

Access?	Public
Smallest geographic unit available?	By individual school
States included?	Washington
Topic?	Education
Most recent year available?	2015
Raw data available?	Yes
AI/AN specific data available?	Yes
Corrected for racial misclassification?	No

Common Core of Data (CCD) State Dropout and Completion Files

Reports the numbers of dropouts from grade 9-12 and high school completions by state.

Access at: http://nces.ed.gov/ccd/drpcompstatelvl.asp

Summary:

Access?	Public
Smallest geographic unit available?	State
States included?	All
Topic?	Education
Most recent year available?	2010
Raw data available?	Yes
AI/AN specific data available?	Yes
Corrected for racial misclassification?	No

Other

Behavioral Risk Factor Surveillance System

Annual telephone survey conducted by each state to assess prevalence of risk behaviors and preventive health practices. Note: conducting analysis with BRFSS data is somewhat complex and is best done by a trained statistician. IDEA-NW is happy to assist or direct your BRFSS data request.

Access at: http://www.cdc.gov/brfss/

Request additional analyses at: ideanw@npaihb.org

Summary:

Access?	Public
Smallest geographic unit available?	For AI/AN data state only, except by special request
States included?	All
Topic?	Various
Most recent year available?	2013
Raw data available?	Yes
AI/AN specific data available?	Yes, at state level. County only by request.
Corrected for racial misclassification?	No but self-report, multiple race selection allowed

National Healthcare Quality and Disparities Reports

Measures of effectiveness of care, patient safety, timeliness of care, access, and patient centeredness, drawn from a variety of data sources. Data query portal allows customized data queries. Not all measures are available for AI/AN.

Access at: http://nhqrnet.ahrq.gov/inhqrdr/data/query

Summary:

Access?	Public
Smallest geographic unit available?	State
States included?	All
Topic?	Healthcare quality, access, insurance, costs
Most recent year available?	2012 for most measures
Raw data available?	No
AI/AN specific data available?	For some measures
Corrected for racial misclassification?	No

Cancer Registry Data - IDEA-NW

The IDEA-NW project at NWTEC conducts regular data linkages with Idaho, Oregon and Washington cancer registries and retains the complete files for analysis.

Access fact sheets and reports at: http://www.npaihb.org/epicenter/project/reports

Request additional analyses at: ideanw@npaihb.org

Summary:

Access?	Fact Sheets and reports, other analyses by request
Smallest geographic unit available?	Down to county depending on population size
States included?	Idaho, Oregon and Washington
Topic?	Cancer
Most recent year available?	2013
Raw data available?	No
AI/AN specific data available?	Yes
Corrected for racial misclassification?	Yes (only source for this)

Demographic

US Census - American FactFinder

The U.S. Census data sets provide primarily demographic information on people, education, employment, income, housing, poverty, health insurance, etc. American FactFinder is the web portal to census data.

Access at http://factfinder.census.gov/faces/nav/jsf/pages/index.xhtml

Summary:

Access?	Public
Smallest geographic unit available?	Down to census block if population is large enough
States included?	All
Topic?	Demographic (some health insurance information included)
Most recent year available?	2010
Raw data available?	No
AI/AN specific data available?	Yes
Corrected for racial misclassification?	No but collected through self-report with multiple race allowed

American Community Survey – American FactFinder

The ACS is a sample survey rather than a census, sent to about 3% of households each year. Covers more topics than the census but sample size limits local level data in some cases. Also accessed through American FactFInder.

Access at http://factfinder.census.gov/faces/nav/jsf/pages/index.xhtml

Summary:

Access?	Public
Smallest geographic unit available?	Down to county if sample size is large enough
States included?	All
Topic?	Demographic, disability, health insurance, employment
Most recent year available?	2014
Raw data available?	No
AI/AN specific data available?	Yes
Corrected for racial misclassification?	No but collected through self-report with multiple race allowed

Published Health Studies

Academic journals can be a good source of data. Some may contain descriptive information about your population or a similar one, and this is often the best place to look for information about interventions and programs that have been successful in addressing a particular health issue your community might be facing.

The best source for academic journals is the National Library of Medicine's PubMed website. Through PubMed you can search more than 24 million citations. However, you may find that only the abstract is available for free, while the full text of the article requires payment.

There is an Indian Health Service portal to access the National Library of Medicine, which allows much broader access to full text published articles. IHS employees can access it using their IHS credentials; for others, contact the librarian to request access, if eligible.

IHS National Library of Medicine portal: http://nihlibrary.ors.nih.gov/ezproxy/ihs.htm

For those who are not IHS employees, contact Diane Cooper, NLM librarian, at Diane.Cooper@ihs.gov to ask if you are eligible to receive a username and password.

Local Data Collection

Every organization that serves clients has an opportunity to collect and utilize data from your own organizations. Combining this locally collected data with national data can provide a more complete and compelling picture of what is happening in the community.

Local data collection can include:

- Needs assessment surveys
- Client demographic information
- Counts of services provided or numbers of clients served
- Numbers of clients served with specific disease conditions
- Program evaluation
- Medical billing records
- Patient satisfaction surveys
- Observational studies

The Northwest Tribal Epicenter's WEAVE-NW program is available to help Northwest Tribes design program evaluation plan and survey instruments for evaluation, community health assessment, patient satisfaction, needs assessment, etc. We can also assist with focus group facilitation and both qualitative and quantitative analysis of data collected. Contact Jenine Dankovchik at jdankovchik@npaihb.org to request assistance.

Common Challenges in Using Secondary Health Data for AI/AN communities

- The data often don't answer the question "why"?

  For example, on page 133 of the Washington AI/AN Community Profile Report, the trend chart shows that death rates from unintentional injury have increased for AI/AN people over the last 20 years. However, this information alone does not tell us the reason behind this increase, which is usually our real question!

- The numbers may be too small to report specific to certain age groups, geographies, etc.

  For example, on page 252 of the Washington AI/AN Community Profile Report, the map does not show homicide rates for every health district. There reason is that there were fewer than five homicide deaths in those districts during that time period, so the rates calculated would be unreliable. Suppressing statistics based on small numbers like this is also done to protect anonymity. We must always remember that data are people and we have a responsibility to treat them ethically and respectfully; reporting on a handful of cases in a specific time and place may make it possible for those people to be identified.

- Changing race data collection methods

  For example, for many years vital statistics only allowed people to choose from three race categories (white, black and other). Since AI/AN race was lumped in with "other" it was not possible to analyze these data for AI/AN communities. Although the data are no longer collected this way for vital statistics, not all datasets or surveys use consistent race definitions, and many have changed over the years making it difficult to compare over time or between data sources.

- Race Misclassification

  Even when race is collected in a consistent way and allows for multi-race responses, these data are only as good as the people who record them. It has been well documented that many public health datasets have high rates of AI/AN race misclassification. This means that people who are in fact AI/AN are recorded in the data as another race, or their records may be missing race all together. When AI/AN people are not counted in the total number of deaths, births, or cases, it results in an artificially low estimate of the disease or death experienced by AI/AN communities.

Working with Limited Health Data

1. Use available data, even if they are not perfect. As long as you educate yourself about what limitations you're dealing with and how they may impact the results, reporting something is almost always better than nothing!
2. Combine multiple years, geographic areas (State-level, regional or all urban areas) or other sub-groups (Examples: combine both American Indians and Alaska Natives, larger age ranges, both genders etc.) to increase small sample size.
3. Seek out data that has been corrected for race misclassification through data linkage (i.e., datasets available through IDEA-NW).
4. In order to answer the "why" questions, it is often helpful to combine several different data sources together (for example, looking at data from the Fatal Accident Reporting System may give a clue about the increasing unintentional injury death rates since we know that the a large share of these deaths happen in motor vehicle crashes).
5. If available, use AI/AN data as a baseline even if disparities are not seen with a usual comparison group or if there is a lack of improvement over time.
6. Consider using different comparison groups or other sources to examine disparities, like those from Healthy People 2020 national health objectives.
7. Use data on a group with similar characteristics to your AI/AN community (income level, education attained, insurance status, other health conditions etc.).
8. Use data on a specific tribe or region even if outside of your area.
9. Use data on related health outcomes (Example: If lacking breastfeeding data, share other available maternal and child health indicators).
10. Search for relevant reports or academic journal articles.
11. Include notes stating where the data come from and describe the known limitations and how they impact the results shared.
12. Use limited data to advocate for improvements and to justify the need for your work.

Ideas for Improving the Quality of Health Data

At the clinic level

1. Include questions about race/ethnicity when collecting health and demographic information.
2. Train any staff that collects race/ethnicity information about the importance of assuring accuracy – educate them about what this information will be used for.
3. Have clear policies and procedures for reporting notifiable diseases and assure training of appropriate staff.
4. Examine current data collection practices (for billing, etc.). Consider what may not be necessary or helpful and stop collecting. Consider what would be helpful to know about your patient population and develop system for easy data collection and analysis.
5. Plan carefully before any change or new data collection. Start with the question *what do we want to know?* and work backward in determining what information to collect and how to collect it. Remember short-term data collection projects can also be helpful.

At the community level

1. Make multiple connections with your local health department. Advocate on behalf of AI/AN living in your area to assure data availability. AI/AN-specific data should be available at a minimum to you and the local urban AI/AN community, and preferably in public reports
2. Work with health departments to develop ways of improving response rates of AI/AN in your community to beneficial surveys, so data can be accessed
3. Work with other local AI/AN groups to advocate for improved data quality. Consider hosting community groups to discuss priority health needs – this could be an opportunity to both present known data and to gather information about the health needs felt by community members.

At the national level – Advocate for:

1. Public and private health agencies receiving funding or reimbursement from the Federal government should collect and publicly report data on race, ethnicity, gender, and primary language. Data should be used to assess health care access and quality as well as progress toward eliminating health disparities for AI/AN.
2. Data collection should be standardized nationally so that all Federal, State and/or Private institutions use the same race and ethnicity categories. At minimum, data collection on race and ethnicity must comply with the 1997 Office of Management and Budget Regulations, to collect

data on American Indians and Alaska Natives, Native Hawaiians and Pacific Islanders, Asian Americans, African Americans, and Hispanic/Latino Americans.

3. The Federal government should support data collection by ethnic sub-groups, which may require small, community-based, localized efforts. The Federal government needs to fund and work with community based organizations, Tribal Governments, Tribal and Native Epidemiology Centers, and Tribal Colleges and Universities who should not only collect these data but assure adequate distribution, utilization and reporting back to the specific sub-group.
4. Funding needs to be provided for over-sampling and national surveys and longitudinal studies of AI/AN.
5. Health Information Technology, Electronic Health Records and Electronic Medical Records, should have the capacity to support health care providers to collect data on race, ethnicity, gender, and primary language.
6. Research projects should reflect the diversity of the American public by deliberately integrating participation and/or involvement of researchers and populations from all racial and ethnic backgrounds.

Other Resources

- Other ideas for support
    - Urban Indian Health Institute (http://www.uihi.org)
    - Free webinars, seminars and classes offered by universities such as
    - Northwest Center for Public Health Practice at the University of Washington: http://www/nwcphp.org/training/courses
    - Maternal and Child Health Analytic Skills Online at: http://www.uic.edu/sph/dataskills
    - Free online resources offered by government agencies and others, such as the following:
        - Department of Health and Human Services, Principles of Infectious Disease Epidemiology at: http://www.dhss.mo.gov/EPI/index.html