

Oregon Tribal Survey Modernization Project

**Northwest Portland Area Indian Health Board
Northwest Tribal Epidemiology Center**



NPAIHB

Final Report to Oregon Health Authority

July 2021



NORTHWEST PORTLAND AREA
INDIAN HEALTH BOARD

Table of Contents

<i>Acknowledgments</i>	2
<i>Oregon Tribal Survey Modernization Project Personnel</i>	3
<i>Executive Summary</i>	4
<i>Background</i>	9
NPAIHB and NWTEC	9
Tribal Nations and the American Indian and Alaska Native People of Oregon	10
Tribal Sovereignty	11
Defining American Indian and Alaska Native	12
Project Background	12
<i>Tribal Workgroup Feedback</i>	17
Survey Classifications of AI/AN	17
Current BRFSS Methodology	19
Tribal BRFSS Review	22
Literature and Data Use Review	27
<i>Recommendations</i>	30

Acknowledgments

The Northwest Portland Area Indian Health Board (NPAIHB) would like to express our sincere gratitude to the tribal workgroup members who gave their time and knowledge to this work, and the Northwest tribes who supported their participation in this project. Many thanks as well to the project team and other NPAIHB staff who provided input and guidance, including Victoria Warren-Mears, Director of the Northwest Tribal Epidemiology Center (NWTEC), and Sujata Joshi, Project Director, Improving Data & Enhancing Access-NW (IDEA-NW).

We are also grateful to the staff of the Program Design and Evaluation Services (PDES) unit within the Oregon Public Health Division and the Multnomah County Health Department, especially Kusuma Madamala and Julia Dilley, for their encouragement and invaluable assistance during the project period.

This project was funded by the Oregon Health Authority under contract 162810-1. The content of this report, including recommendations, solely represents the work of the NPAIHB, and do not reflect the views of the Oregon tribes, Oregon Health Authority, PDES, the State of Oregon, or any other agency, organization, or governmental entity.

For more information about the work of the NPAIHB and NWTEC, please visit www.npaihb.org.



**NORTHWEST PORTLAND AREA
INDIAN HEALTH BOARD**
Indian Leadership for Indian Health

Northwest Portland Area Indian Health Board

Northwest Tribal Epidemiology Center
2121 SW Broadway, Suite 300
Portland, OR 97201
503-228-4185

Oregon Tribal Survey Modernization Project Personnel

NPAIHB/NWTEC Project Team

Bridget Canniff, MALD, CPH
Project Director, Public Health Improvement & Training (PHIT)

Kimberly Calloway, DVM
Project Specialist, Public Health Improvement & Training (PHIT)

Kerri Lopez, BA
Project Director, Western Tribal Diabetes, NW Tribal Comprehensive Cancer, and BOLD Projects

Natalie Roese, MPH
Biostatistics Contractor, Improving Data & Enhancing Access-NW (IDEA-NW)

Tribal Workgroup

Nicole Barney, MS
PhD Candidate, Special Education
Graduate Teaching Fellow, Special Education and Clinical Sciences
University of Oregon / Klamath Tribal Member

Pamela Gutman, MPH, MS*
Public Health Improvement Manager
Cow Creek Band of Umpqua Tribe of Indians

Jessica Hamner, MPH
Public Health Improvement Coordinator
Coquille Indian Tribe

Obinna Oleribe, DrPH, FRCP, MBA
Health General Manager
Klamath Tribes

Richie Thomas, MEd
PhD Candidate, Special Education
Graduate Teaching Fellow, Human Development
University of Oregon

*Left tribal employment and workgroup in May 2021

Executive Summary

Background

The Northwest Portland Area Indian Health Board (NPAIHB) is a tribally-designated organization formed in 1972 that serves the 43 federally-recognized tribes in Idaho, Oregon, and Washington, each of which appoints a delegate to NPAIHB. The Northwest Tribal Epidemiology Center (NWTEC or the EpiCenter) was formed in 1996 as a department of the NPAIHB and is guided by the Public Health Committee of the NPAIHB, reporting to the tribal delegates.

Oregon is home to nine federally-recognized tribes:

- Burns Paiute Tribe
- Confederated Tribes of Coos, Lower Umpqua and Siuslaw Indians
- Confederated Tribes of Grand Ronde
- Confederated tribes of Siletz Indians
- Confederated Tribes of the Umatilla Indian Reservation
- Confederated Tribes of Warm Springs
- Coquille Indian Tribe
- Cow Creek Band of Umpqua Tribe of Indians
- Klamath Tribes

Each tribe has a unique history and culture, and is a sovereign government with its own elected leaders and policies for enrollment of its citizens. The state also has a sizeable and thriving population of AI/AN people living in urban areas and elsewhere throughout the state.

Tribal sovereignty is the inherent authority of a tribe to govern and protect the health, safety and welfare of tribal citizens. As sovereign nations, tribes are the owners of data for their citizens and should have primary control and voice in the use, interpretation, and disposition of data related to their citizens.

It is important to note that there are many ways to define American Indian and Alaska Native (AI/AN) for data analysis purposes. As tribal citizenship is a political status, this makes the analysis and interpretation of data on AI/AN people more complex and different from analyses on other race and ethnicity groups. The NPAIHB and NWTEC use a broad definition of AI/AN, cross-referencing data with tribal registries to ensure all AI/AN are counted when providing data to tribes.

Project Overview

The purpose of the Oregon Tribal Survey Modernization workgroup was to review survey data from the Oregon Behavioral Risk Factor Surveillance System (BRFSS) and Oregon Health Teens (OHT) survey and highlight priority analyses, identify knowledge gaps, and generate topics and methods that can provide additional context to the results for AI/AN communities in Oregon and others who use the data. Given the condensed time frame of this work, our desire to not duplicate past or ongoing tribal data collection, and the need to respect tribal data ownership and sovereignty, the NPAIHB tribal workgroup elected not to engage in primary data collection and instead to review the methods and supplemental data of previously conducted Tribal BRFSS surveys.

The NPAIHB assembled a self-selected group of five participants for the project workgroup who responded to a general call for participation sent to tribal health leaders and staff at the nine Oregon tribes and NARA-NW, the Urban Indian Health Program in Portland. These five workgroup members were joined by four NPAIHB staff from the NWTEC. The NPAIHB hosted five two-hour Zoom meetings between May and July to discuss the OHT and BRFSS data as it relates to the AI/AN community and tribes.

The primary limitations of the workgroup process include the lack of representation from all nine Oregon tribes and urban Indian populations, as well as the condensed time frame and additional burdens facing public health professionals during the COVID-19 pandemic.

Tribal Workgroup Feedback

Defining AI/AN

The “best race” method of race classification does not accurately reflect the characteristics of the AI/AN population. Under this method, many respondents selecting multiple race/ethnicity who identify as AI/AN and/or are members of Oregon tribes are reclassified into other race or ethnicity categories, leading to underrepresentation of AI/AN respondents in survey data.

BRFSS Methods

The BRFSS survey is not conducted in a way that effectively reaches AI/AN communities. Outgoing calls from Oregon Health Authority are unlikely to be answered by potential AI/AN respondents.

Tribal Use of BRFSS Data

For members of the workgroup who are tribal health program staff, the BRFSS data are primarily useful only at the county level. They are therefore both too broad to be reflective of tribal members and exceedingly complicated to use for tribes whose service population is spread across multiple counties in Oregon.

It is important to note that while many tribes use BRFSS data to support funding applications, the analysis and reporting of tribe-specific BRFSS or OHT data by OHA or another non-tribal agency or organization to gain funding without tribal consultation would be an inherent tribal sovereignty conflict.

Additional funding is needed to meet pre-determined health needs, and additional surveys assessing need and amplifying disparities are not of great use to AI/AN communities.

Lack of Meaningful Context

Many OHT questions lack important cultural context or exclude non-Western practices. There is not sufficient follow-up on why students' needs are not being met, denying actionable information to alleviate barriers to healthcare access, for example.

Data Gaps

Some members of the workgroup were concerned about substantial missing data in the OHT and the lack of additional information on why questions were not answered.

The OHT and other future surveys would benefit from an increased focus on protective factors, particularly those that may come from involvement in cultural and tribal activities. Additional questions surrounding involvement in tribal and other cultural activities are needed.

Given the underlying difficulty of working with small sample sizes among AI/AN populations and tribes, greater efforts to incentivize school participation in OHT will yield more representative and useful data.

Tribal BRFSS Review

Upon request, the NPAIHB and the NWTEC support tribes in conducting tribe-specific BRFSS surveys that allow tribes to have full ownership of the data, ask questions relevant to their particular tribe and community, and reach tribal members more effectively and efficiently.

For tribal BRFSS projects, tribes have hired and trained tribal project site coordinators and tribal interviewers and provided a computer with needed survey and statistical software, or have contracted for these services with NWTEC and other public health professionals. BRFSS surveys have been adapted for use by multiple tribes to include information on point of care, use or need of specific services, follow-up questions on barriers to care, and participation in cultural activities.

Past tribal BRFSS participation was increased through community outreach, updating tribal phone registries, allowing for scheduled or in-person interviews, calling from a trusted phone number and compensating participation. Resulting data from Tribal BRFSS surveys have consistently provided highly relevant and actionable information to tribes about the needs of tribal members.

Data Use and Literature Review

Tribes are wary of data on AI/AN people being incorrectly understood or taken out of context, whether maliciously or unintentionally, when data are interpreted and reported by entities working outside of tribal contexts. This includes data reported by local and state public health agencies. datasets. To better understand where BRFSS and OHT AI/AN data are referenced, we reviewed data reports publicly available on OHA's website and conducted a literature review.

In the example of student absenteeism, OHA reports would benefit from concrete explanations of factors that may increase absenteeism among disadvantaged communities to better contextualize disparities.

Two studies identified in the literature review discussed the challenges of the "best race" methodology. The "best race" method has the potential to diminish the appearance of health disparities and ignore the burdens facing multi-race respondents in ways that have the potential to skew results.

The workgroup suggests enhanced tracking by OHA of BRFSS data requests and resulting data use to ensure that tribal data is protected.

Workgroup Recommendations to OHA

Actionable Data

- Work with tribes, the UIHP, and NWTEC to convene future discussions with health program staff, tribal leaders, and other stakeholders to better understand data priorities and the need for locally-actionable, tribal-specific data.
- Incorporate non-Western approaches to health and healthcare into survey questions.

Survey Methods

- Partner with tribes and tribal or urban AI/AN organizations to increase BRFSS participation and educate community members about the BRFSS and OHT.
- Include questions on protective factors, particularly involvement in tribal and AI/AN community activities.

Tribal and AI/AN Community Engagement

- Support Oregon tribes in conducting tribal BRFSS surveys.
- Protect tribal data and tribal sovereignty. Consider instituting additional data access requirements for non-AI/AN affiliated researchers and others to track how survey data are used, where data analyses or reports are posted or published, and ensure transparency and oversight by tribal and AI/AN communities.

Next Steps

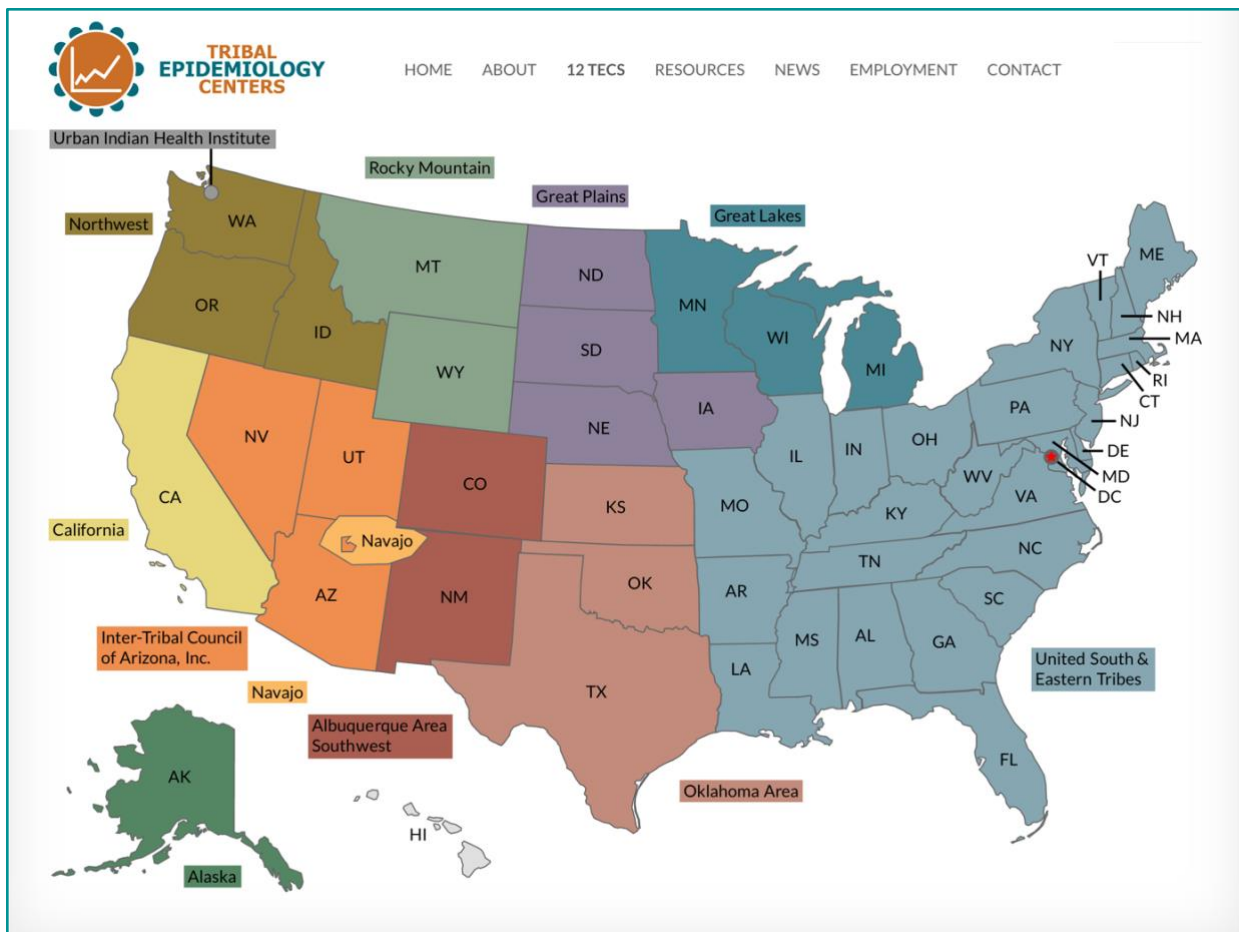
- Seek additional feedback and input from tribes and AI/AN organizations, both from leadership and members of AI/AN communities, on how to improve BRFSS and OHT data quality and useability.
- Continued long-term engagement with AI/AN communities is critical to ensure that the initial recommendations in this report can be refined and expanded. OHA should utilize existing forums and recurring tribal meetings to further discuss survey modernization, but also consider holding listening sessions hosted by and within tribal and AI/AN communities.

Background

NPAIHB and NWTEC

The Northwest Portland Area Indian Health Board (NPAIHB) is a tribal organization formed in 1972 that serves the 43 federally-recognized tribes in Idaho, Oregon, and Washington, each of which appoints a delegate to the NPAIHB. The Northwest Tribal Epidemiology Center (NWTEC) was formed in 1996 as a department of the NPAIHB and is guided by the Public Health Committee of the NPAIHB, reporting to the tribal delegates.

Figure 1: Map of Tribal Epidemiology Centers



Source: www.tribalepicenters.org

Tribal Epidemiology Centers (TECs) were established as [public health authorities](#) for the purposes of the Health Insurance Portability and Accountability Act (HIPAA) through permanent reauthorization of the Indian Health Care Improvement Act (IHICIA) in 2010 (TribalEpiCenters.org). Each TEC functions independently but also as part of a national group called the TEC-Consortium. This status does not alter tribes' public health authority as sovereign nations, but is supportive of it. A US Health and Human Services (HHS) directive gives TECs access to HHS data systems and protected health information and the CDC provide technical assistance. Each Indian Health Service (IHS) Area must have TEC access. This allows TECs to act

as public health authorities at the request of tribes for data and provision of technical assistance.

Tribal Nations and the American Indian and Alaska Native People of Oregon

Oregon is home to nine federally-recognized tribes:

- Burns Paiute Tribe
- Confederated Tribes of Coos, Lower Umpqua and Siuslaw Indians
- Confederated Tribes of Grand Ronde
- Confederated Tribes of Siletz Indians
- Confederated Tribes of the Umatilla Indian Reservation
- Confederated Tribes of Warm Springs
- Coquille Indian Tribe
- Cow Creek Band of Umpqua Tribe of Indians
- Klamath Tribes

Figure 2: Map of Oregon's nine federally recognized tribes



Source: Oregon Health Authority

Oregon has the ninth-largest state-wide AI/AN population (self-reported AI/AN race alone or in combination with one or more other races) by percent of state residents at 2.99%, and the twelfth-largest by number of people at 128,380 (US Census Bureau, 2019a). In addition to tribal citizens residing on or near reservations and tribal lands, Oregon also has a sizeable and thriving population of American Indian and Alaska Native (AI/AN) people living in urban areas and

elsewhere in the state. The urban AI/AN population includes those who may be enrolled in federally-or state-recognized tribes outside of Oregon or descendants of AI/AN people indigenous to the continental US. According to the US Census Bureau American Community Survey (2019b-g), population estimates for AI/AN (alone or in combination) residents of the six metropolitan areas in Oregon are 53,067 in the Portland-Vancouver-Hillsboro, OR-WA Metro Area; 19,800 in the Salem, OR Metro Area; 12,642 in the Eugene-Springfield Metro Area, 6,423 in the Medford, OR Metro Area; 4,342 in the Albany-Lebanon, OR Metro Area; and 3,752 in the Bend, OR Metro Area; for a total estimated urban population of 100,026.

Federally-recognized tribes are recognized by the United States of America as sovereign nations. Under Article I, section 8 of the US Constitution, federally-recognized tribes are entitled to certain federal benefits, services, and protections. Federal Indian reservations are areas reserved by treaty or other agreements with the United States, and the US government holds title to the lands, in trust, for these permanent homelands for tribal nations.

In the 1950s, many Oregon tribes were terminated by the federal government. Termination revoked tribal sovereignty and land stewardship responsibility from tribes, often forcibly removing tribal members from their native land and shuttling them to poor urban areas. Six of the terminated Oregon tribes were later restored by the federal government. The terminated and restored tribes served by NPAIHB are the Confederated Tribes of Coos, Siuslaw & Lower Umpqua Indians; the Confederated Tribes of Grand Ronde; the Confederated Tribes of Siletz Indians; the Coquille Indian Tribe; the Cow Creek Band of Umpqua Tribe of Indians; and the Klamath Tribes. Confederated tribes comprise multiple bands, which were formed when the federal government moved decentralized villages (tribes) to a single shared location, often with disregard to ongoing and historical adversarial relationships.

The state of Oregon has had longstanding inter-governmental relationships with tribes and AI/AN communities, with a particularly strong emphasis on state-tribal relations over the last several decades. State agencies, including the Oregon Health Authority (OHA), engage regularly with the nine tribes and NARA-NW, the Portland-area Urban Indian Health Program (UIHP), including through tribal consultation and conferring with the UIHP (OHA Tribal Affairs).

Tribal Sovereignty

Tribal sovereignty is the inherent authority of a tribe to govern and protect the health, safety and welfare of tribal citizens. American Indians and Alaska Natives are citizens of sovereign tribal nations that have a unique legal and political relationship with the federal government that has been reaffirmed through numerous treaties, court cases, and Executive Orders. Tribal citizens are also citizens of the state in which they live and of the US, and all three governments – tribal, state, and federal – have a responsibility for the health and welfare of tribal members (Oregon Health Authority Tribal Affairs).

Tribal sovereignty means that each tribe is treated as a nation within a nation. These nations' members make their own laws within the tribe, act on their own behalf and sustain their living by adhering to tribal laws and regulations. Tribal sovereignty ensures the right for tribes to

choose their own future. Tribes are self-governing indigenous nations with legal, political, cultural, and spiritual authority. As sovereign nations, tribes are the owners of data for their citizens and should have primary control and voice in the use, interpretation, and disposition of data related to their citizens.

Defining American Indian and Alaska Native

There is no single definition of American Indian/Alaska Native. While tribal citizenship is a political identity, state and federal systems do not systematically collect data on this status in a meaningful way. The race data that are collected by state and federal agencies are used to approximate tribal membership but do not address the nuances of AI/AN identity. For more discussion on this topic, see the Survey Classifications of AI/AN section on page 17 of this report.

"American Indian and Alaska Native tribal affiliation guidelines are varied and often based on complex tribal histories and sociopolitical processes which have led to multiple terms and levels of AI/AN identity. In addition, Tribes, Pueblos, and Nations can be federally recognized, state recognized, and unrecognized by either state or federal government, and people can self-identify as being AI/AN."

Haozous et al. (2014), [Blood Politics](#)

When producing data reports, the NPAIHB and the NWTEC opt to classify AI/AN race using any mention of American Indian, Alaska Native or tribal affiliation. Additionally, through the IDEA-NW Project (www.npaihb.org/idea-nw), the NWTEC cross-references state datasets with tribal registries in order to correct for race misclassification and provide accurate public health reports to Northwest tribes. AI/AN race is generally underreported on death certificate and state health databases, with estimates of misclassification ranging from 10-60% depending on the dataset (Jim et al., 2014). Misclassification is most often due to incorrect observations and assumptions by healthcare workers, instead of asking individuals to self-identify their race and ethnicity. Together, these methods allow the NWTEC to correct for racial misclassification and spotlight the people that we serve.

"American Indians and Alaska Natives are often incorrectly classified as another race (usually White) in vital statistics, cancer registries, and other public health datasets. In the Northwest, AI/AN misclassification in health datasets can range from 10-60%... Without accurate data, tribes are limited in their ability to identify and allocate resources to the areas of greatest need."

[IDEA-NW](#), NPAIHB/NWTEC

Project Background

The Behavioral Risk Factor Surveillance System (BRFSS) and Oregon Healthy Teens (OHT) surveys are core components of Oregon Public Health Division's (OPHD) health assessment

system and are essential tools for program and policy planning, federal grant applications and legal advocacy. NPAIHB/NWTEC partnered with the Oregon Public Health Division and Program Design and Evaluation Services (PDES) to form a Survey Modernization Tribal Workgroup to gather feedback from tribal and AI/AN communities on the methods and data quality of the BRFSS and OHT surveys. The purpose of the workgroup was to review the survey data and highlight priority analyses, identify knowledge gaps and generate topics and methods that can provide additional context to the results for AI/AN communities in Oregon and other users of the data.

Given the condensed time frame of this work, our desire to not duplicate past or ongoing tribal data collection, and the need to respect tribal data ownership and sovereignty, the workgroup elected not to engage in primary data collection and instead to review the methods and supplemental data from previously conducted tribal BRFSS surveys. Six NPAIHB member tribes have completed a tribal BRFSS. The tribal BRFSS surveys were created as collaborative efforts between the NPAIHB and tribal administrations. While the state BRFSS uses phone calls as the primary data collection method, three of the tribes used phone calls, and two used the “door to door” method and conducted the survey in-person.

Limitations

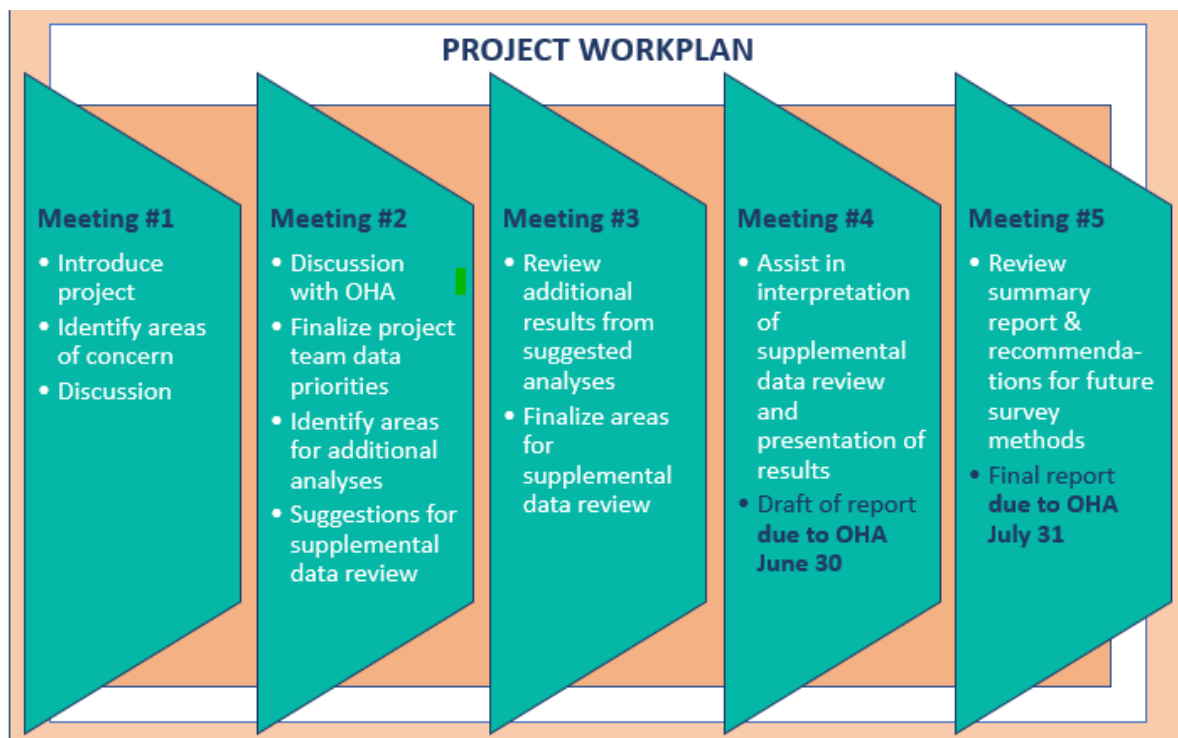
Some of the limitations of this effort that we wish to highlight are:

- The views articulated by the workgroup reflect the perspectives of a small number of tribal health professionals and tribal members from a subset of Oregon tribes. Future workgroups and dialogue should incorporate urban Indian perspectives and feedback from all Oregon tribes.
- The scope of our project was somewhat limited by the relatively short duration of our contract with OHA, which started in November 2020. After a planning and outreach period between November 2020 and February 2021, the NPAIHB workgroup met five times between March and June 2021.
- Given this limited time frame and the unique considerations that must be taken when acquiring, requesting, and accessing tribal data, the workgroup decided early on to rely on secondary data for analysis and interpretation. The use of secondary data greatly reduced the comparability of the BRFSS/OHT data and the supplemental data review. While the workgroup discussed recently-used tribal BRFSS survey methods, the only publicly available tribal BRFSS data for presentation and discussion was from 2001. Accessing more current tribal BRFSS data would have required tribal approval, which was not feasible within our timeline.
- Other limitations included the departure of one workgroup member from her tribal public health position midway through the project timeline, as well as scheduling challenges, which impacted full workgroup attendance and continuity of discussion across meetings. The additional workload of the COVID-19 pandemic further stretched the availability of tribal health professionals and NPAIHB/NWTEC staff.

Workgroup Formation and Meeting Summaries

The NPAIHB put out a call for workgroup members to all nine Oregon tribal health programs and NARA-NW. This outreach included emails to Tribal Health Directors and tribal public health staff, targeted outreach to the staff of the 8 tribes and NARA-NW participating in NPAIHB's Oregon Tribal Public Health Improvement and assessment work under our primary contract with OHA, and announcements during NPAIHB meetings including our Quarterly Board Meeting in April 2021 and weekly tribal COVID-19 update sessions. Our goal was to recruit at least 5 workgroup members. As part of our process of identifying potential workgroup members, we asked them to complete a brief survey to identify key topic areas of interest.

Figure 3: Survey modernization project meeting workplan



The tribal workgroup's process unfolded over six months, from February through July 2021:

- Pre-Meeting Survey: A majority of workgroup members identified key topic area priorities as adverse childhood events (ACEs), chronic health conditions, suicide and behavioral health. Additional topics of interest identified are listed below. Cross-tabulations on all topic areas for BRFSS and OHT were calculated and graphed for discussion.
 - **Adverse childhood events (ACEs)**
 - **Chronic health conditions**
 - **Suicide**
 - **Behavioral health**
 - Substance use disorder

- Physical activity and nutrition
 - Healthcare access
 - School attendance
- Meeting #1 (March 1st): The workgroup reviewed the goals and objectives of NPAIHB's Oregon Survey Modernization project. There was initial concern from some workgroup members about the purpose of the project, particularly around supplementary AI/AN data collection, data ownership, and the potential lack of ability for all tribes to provide context for the data. There were concerns about the sharing of tribal data without proper tribal approvals, whether reports and data on AI/AN people and tribal members would be public-facing, and how the data would be protected. NPAIHB staff presented BRFSS and OHT data on some of the key health topics identified in the pre-meeting survey and held a facilitated discussion with workgroup members, with a focus on the importance of context in the survey questions.
 - After the first meeting, the NPAIHB project team met individually with workgroup members to discuss concerns around the overall project goals and challenges of primary data collection, and to identify questions to be addressed by OHA staff at a future meeting.
 - Meeting #2 (March 18th): The NPAIHB invited OHA to the second meeting to present on the purpose of the Oregon Survey Modernization project and provide an opportunity for discussion. The workgroup reviewed initial data analyses and discussed OHT and BRFSS methods.
 - Workgroup members identified questions for suggested analyses between Meeting #2 and Meeting #3. Given the specialty and interests of the workgroup, the suggested analyses focused on the experiences, behaviors and environmental factors facing AI/AN teens in Oregon. Members of the workgroup listed the following questions (and associated OHT variables) for data review.
 - How is the general health of AI/AN teens in Oregon?
 - How is the mental health of AI/AN teens in Oregon?
 - How are AI/AN teens performing at school?
 - To what extent do the schools that AI/AN teens in Oregon attend feature harmful, dangerous or criminal behavior?
 - To what extent do AI/AN teens in Oregon suffer from money concerns?
 - How often do AI/AN teens in Oregon get enough sleep?
 - Do AI/AN teens in Oregon get sufficient exercise?
 - How often do AI/AN teens in Oregon eat healthy food?
 - To what extent do AI/AN teens in Oregon engage in risky or harmful behavior?
 - To what extent do AI/AN teens in Oregon use legal or illegal drugs?

- To what extent do AI/AN teens in Oregon experience abuse?
 - To what extent are AI/AN teens engaged in their community?
- Meeting #3 (March 29th): The primary goal of this meeting was to review results from the suggested analyses submitted by workgroup members. The discussion focused on the importance of presenting missing values in survey results and the ambiguity and lack of meaningful context in many of the questions. The workgroup discussed supplemental data that was available for review.
- Meeting #4 (April 26th): Julia Dilley of PDES presented the results of the Oregon BRFSS Pilot Study. The workgroup reviewed comparable questions in the Oregon BRFSS and a sample tribal BRFSS, and discussed overarching themes of the data report.
- Meeting #5 (June 25th): Kerri Lopez of the NPAIHB presented on the tribal BRFSS project and results. The workgroup reviewed the results from the literature review and highlighted articles. We shared the current draft of this project report to OHA, and the workgroup was given two weeks to provide feedback.
- Post Meeting Period: workgroup members reviewed and provided feedback on this final report.

Data and resources utilized during meetings:

- BRFSS 4-year race reporting file
- OHT 2019 data file
- Overview of BRFSS and OHT topic areas with sample questions
- OHT suggested analyses requested from workgroup members after Meeting #2 (see Appendix B)
- Results of Oregon BRFSS Pilot Study
- Tribal BRFSS sample questions
- De-identified tribal BRFSS report
- Literature review of OHT/BRFSS data uses and data reports

Survey Classifications of AI/AN

The OHT and BRFSS surveys utilize multiple methods for race classification, including tribal affiliation, American Indian indicator and a “best race” classification. The “best race” classification is determined by the question, “Which one of these groups would you say best represents your race?” The classification used to define AI/AN respondents has a dramatic effect on the sample size. While 1,757 respondents identified themselves as American Indian in the 2016-2019 BRFSS, only 656 respondents are classified as AI/AN under the “best race” classification, with 976 respondents being classified as non-Hispanic White and 125 classified as other races or ethnicities. Similarly, among respondents who are enrolled members of an Oregon tribe, 18 were not categorized into AI/AN under the “best race” classification. This reclassification poses a tribal sovereignty conflict as members of Oregon tribes are by definition AI/AN and should be reported as such. The Bureau of Indian Affairs (BIA) notes that “there is no single federal or tribal criterion or standard that establishes a person's identity as American Indian or Alaska Native” but that a distinction must be drawn “when the term “American Indian” is used in an ethnological sense versus its use in a political/legal sense.” In the BRFSS race-reporting file dataset provided, it is important to note that respondents who specified multiple races but did not choose one “best race” category were excluded from the dataset.

Figure 4: American Indian respondents by Best Race classification (BRFSS, 2016-2019)

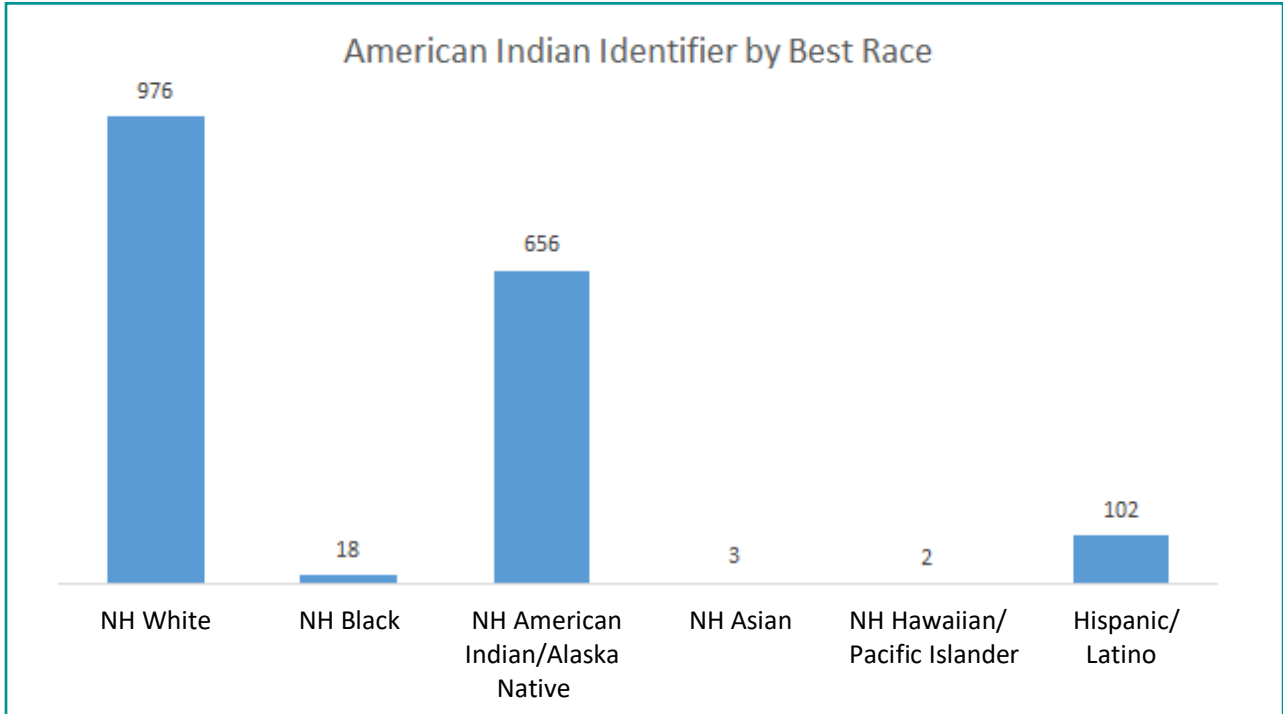
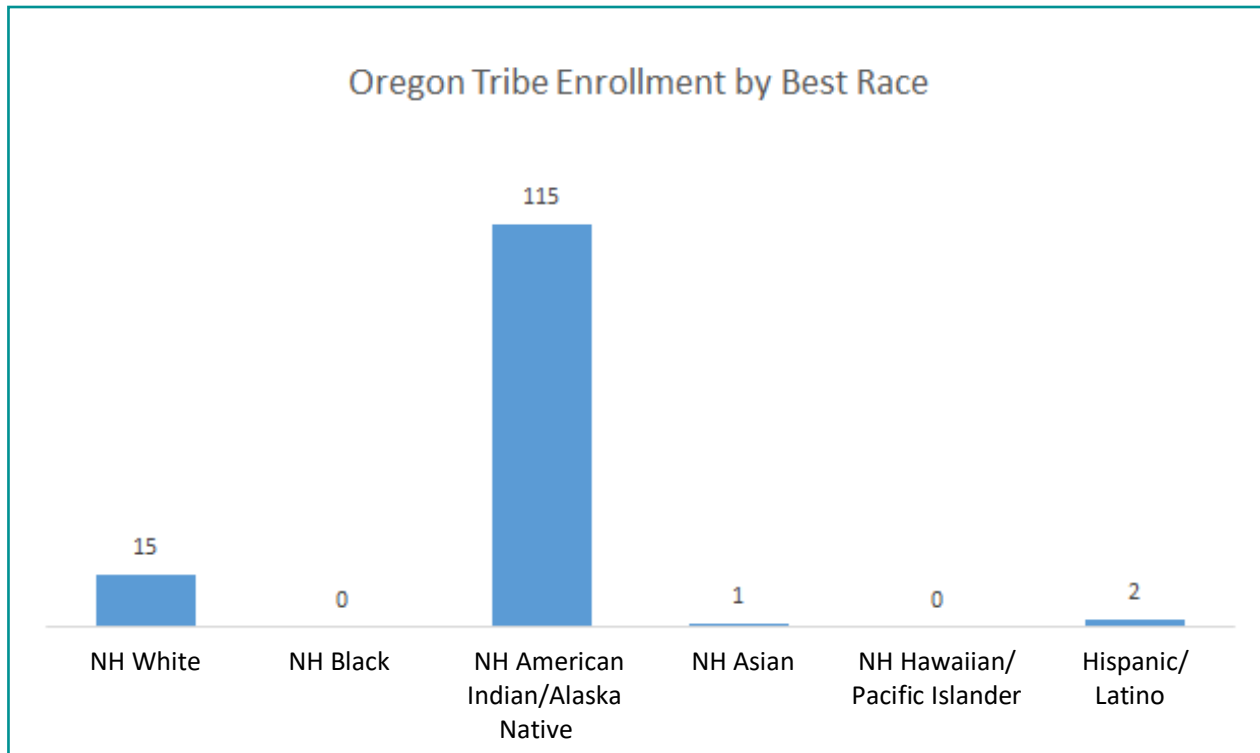


Figure 5: Oregon tribal member respondents by Best Race classification (BRFSS, 2016-2019)



Stratifying the data into “best” or “preferred” race categories is a useful tool for making comparisons across distinct racial groups, but does not accurately reflect the characteristics of the AI/AN population or the political status of tribal members. The workgroup felt strongly that the primary role of improving BRFSS and OHT data for AI/AN communities should be to better inform and best serve Oregon tribes, not to generate more accurate stratifications and comparisons by race for researchers unaffiliated with tribes or AI/AN communities to analyze and distribute. Previous studies have found that allocating White multi-racial BRFSS respondents into the White category, as seen in the BRFSS “best race” method, has the potential to worsen the health profile of White respondents, giving the illusion of decreasing health disparities (Bratter et al., 2011). These definitions and classifications gain additional importance when considering the BRFSS survey methodology, which, among other factors, oversamples and weights respondents in accordance with their race and ethnicity, inherently valuing the responses of some AI/AN and tribal respondents more than those of others.

It is important to understand that tribes may have a variety of uses for BRFSS and OHT data and may have different criteria for identifying AI/AN residents and tribal members. Tribes may be interested in assessing the characteristics of:

- All registered tribal members (both in and outside Oregon)
- Those who utilize their tribal clinic or services
- The wider community residing within the tribal service area.

“In facilitating a tribe’s rights to exercise sovereignty and facilitate good relations, researchers would benefit from having communities decide on inclusion criteria for AI/AN identity such as enrollment rolls, ancestry, or other specific variables as determined by the tribe.”

Haozous et al. (2014), [Blood Politics](#)

The NPAIHB was asked to comment on Oregon’s REALD methodology. REALD will allow respondents to identify their racial and ethnic identities in a wider variety of ways: first generally, and then in specific subcategories groupings that allow for write-in responses. The NPAIHB/NWTEC notes that in addition to American Indian and Alaska Native, the REALD AI/AN umbrella also includes Indigenous Mexican, Central and South American; Canadian Inuit, Metis and First Nation; and other AI/AN. While the latter are Indigenous and Native American, they do not fall under the political/legal category of American Indian/Alaska Native as tribal citizen or descendent, which may result in data inconsistencies.

Current BRFSS Methodology

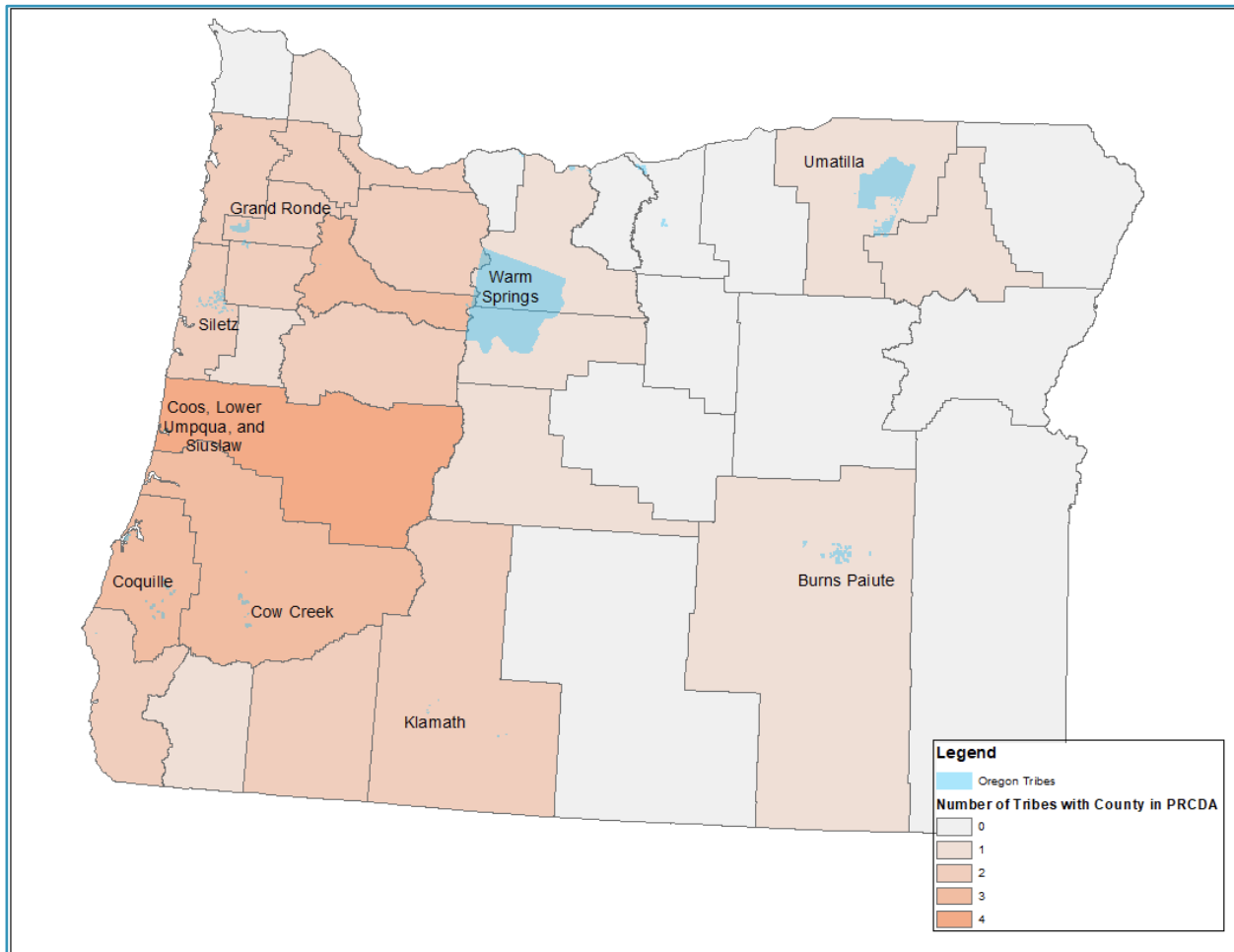
The current BRFSS survey is not conducted in a way that reaches members of AI/AN communities as efficiently as possible. Many Oregon tribes and AI/AN people live in remote parts of the state, where cell phone coverage may be limited, making outreach via phone an unreliable recruitment method. The workgroup emphasized that there is deep distrust in government among AI/AN communities and that cold calls from the state could potentially be traumatic for AI/AN people. Many people are unfamiliar with OHA and the BRFSS, and the name “Oregon Health Authority” does not elicit trust or comfort. The cold-call method implies that the caller already knows who they are and where they are located, and so the respondent may be less inclined to answer honestly. For this reason, the phone survey methods might be less valid than online survey methods where there is greater anonymity. This feedback was affirmed by the results of the Oregon BRFSS Pilot study, which reached the majority of its AI/AN respondents through paper or online surveys and had minimal success with either inbound and outbound calls.

Tribal Use of BRFSS and OHT Data

Oregon tribes generally are interested in data from their associated Purchased/Referred Care Delivery Areas ([PRCDA](#)). PRCDA are defined as counties that include a tribal reservation or have a common boundary with a tribal reservation, and are generally considered to delineate tribal service areas for healthcare delivery. One tribe may be associated with multiple PRCDA counties, and one PRCDA county may include members from multiple neighboring tribes. The following map shows Oregon PRCDA counties and associated tribes. For members of the workgroup working directly with tribes, the BRFSS data is primarily useful only at the county level and is therefore both too broad to be reflective of tribal members and exceedingly complicated for tribes whose members span across multiple counties. Using the data based on county designations requires complicated cross-tabulations and lacks important context, as not all AI/AN respondents within a county may belong to the nearest tribe and not all tribal

members live within neighboring counties. Workgroup members suggested that OHA conduct an assessment to ask the tribes directly whether they utilize BRFSS and OHT data, and how they wish to define their tribal service areas.

Figure 6: Map of Oregon tribes (blue) and PRCDAs (orange)



As part of our process, NPAIHB staff reached out to other projects within our organization that work with AI/AN teens to see how and when OHT data has been utilized. While OHT/YRBS has occasionally been used as an evaluation metric, these projects prefer to rely on internal surveys, focus groups, and adapted data sources such as the [Oregon Native Youth Survey](#) (ONYS) that can provide culturally-relevant data. ONYS is based upon the OHT, the Communities That Care (CTC) survey developed by Hawkins and Catalano at UW Seattle, and the Voices of Indian Teens survey (Dr. Spero Manson, PI). The Native American Rehabilitation Association of the Northwest (NARA-NW), which has been using the survey tool, added a peer suicide knowledge section from the Lifelines PreTest Questionnaire and additional questions about protective factors based on the concept of resiliency. ONYS was also reviewed for cultural appropriateness by a cultural advisory team at NARA-NW and is designed to be used along with focus groups for a better understanding of how the actual intervention activities are experienced by the youth.

While many tribes refer to BRFSS data in their funding applications, the use of AI/AN BRFSS or OHT data by non-AI/AN organizations in funding requests and project proposals, without consulting or conferring with tribes or UIHPs, can be considered problematic. Workgroup members felt strongly that tribes are very aware of the health inequities for AI/AN people and communities in Oregon, and that community-based participatory research and public health approaches that include AI/AN people at all stages should be promoted and supported. It is not enough that data be actionable, but also that the funding invested in addressing documented health inequities be flexible enough, and prioritize community-based recipients, to allow tribes and AI/AN-led organizations to guide the work.

“There is a need for more funding to meet the needs that have already been determined, and not simply more surveys to further assess needs and exemplify disparities.”

Tribal Workgroup Member

Lack of Meaningful Context

Many OHT questions miss important cultural context. One example is the following OHT survey question: “During the past 30 days, did you ever sleep away from your parents or guardians because you were kicked out, ran away, or were abandoned?” A larger proportion of AI/AN teens responded “Yes” to this question than NHW teens, which taken out of context might be interpreted to mean that AI/AN teens face higher levels of conflict or neglect than NHW teens. However, for many AI/AN teens, who may live or often stay with other relatives often, sleeping away from home to stay with another family member during conflict may be a commonplace event, perhaps even a method of conflict management. The question as phrased could easily be interpreted as a standard coping strategy by AI/AN teens and point to higher conflict in AI/AN households by researchers who do not work in tribal communities.

The OHT question “I can work out my problems” was another example of a question that may be interpreted one way by AI/AN teens and another way by potential researchers. This question is part of the Positive Youth Development (PYD) section which aims to assess student’s physical, emotional and social support. While the intent of the question is to assess student well-being and self-efficacy, the lack of contextual information for both the student and researchers makes it difficult to extrapolate meaningful information from the resulting responses.

The specificity of healthcare language in the OHT survey excludes non-Western modalities. For example, the question “During the past 12 months, did you have any physical health care needs that were not met? (Count any situation where you thought you should see a doctor, nurse, or other health professional.)” does not include an option to specify care from traditional healers. Including non-Western approaches in this question or asking a second question about access to traditional healers or other non-Western practitioners would more accurately capture the range of care students receive and may elucidate differences in students’ access to Western and non-Western care.

Additionally, the OHT questions do not follow up with questions on why students are not able to access needed physical or mental healthcare. In order for the data to be actionable, more information on the reasons for unmet physical and mental health care needs are required, above and beyond the cost of care. Additional barriers to care may include: lack of insurance, inability to find a provider, owing money to the provider, transportation, difficulty finding/scheduling an appointment and lack of a care provider. See the tribal BRFSS section below for referenced sample questions.

Data Gaps

The tribal workgroup discussed the lack of information about missing data in the OHT. Many questions did not have an option for “I prefer not to answer.” or “I do not understand the question.” This information would be crucial to understanding how AI/AN students interpret the questions and where potential issues in question phrasing may result in non-response. This issue was exemplified in inconsistent responses around disability, in which a missing response may point to a “soft no.” Pilot-testing some of these additional response options, or getting direct feedback from students who did not answer certain questions, could help uncover the reasons for missing data.

“Are there additional questions which could be added to the OHT survey to better show respect for tribal communities, or to better highlight the strengths of tribal communities?”

Tribal Workgroup Member

Workgroup members identified the positive youth development question “I volunteer to help others in my community” as an important indicator of perceived community engagement. Additional questions on community engagement would inform tribal and AI/AN organizations about student interest and participation in culturally-specific opportunities within their communities. OHT would benefit from an increased focus on protective factors particularly those that may come from involvement in cultural and tribal activities. Additional questions surrounding involvement in tribal and other cultural activities are needed.

The workgroup wanted to know how school participation in the OHT survey is encouraged, given that the response rate is only 30%. We understand that the OHT is not incentivized and that the low participation rate may be due to a lack of support for schools to conduct the surveys. Given the underlying difficulty of working with small sample sizes among AI/AN populations and tribes, greater efforts to increase school participation will yield more representative and useful data.

Tribal BRFSS Review

Upon request, NWTEC supports tribes in conducting tribe-specific [tribal BRFSS surveys](#) that allow tribes to have full ownership of the data, ask questions relevant to their particular tribe and community, and reach tribal members more effectively and efficiently. For example, the

[Cowlitz Tribal BRFSS](#) allowed the Cowlitz Tribe to investigate colorectal cancer screening rates among tribal members and evaluate the impact of the tribe's Colon Health Program. Each tribal BRFSS could be tailored to assess the unique health needs and services of each tribe:

- Tribes were funded to hire and train tribal project site coordinators and tribal interviewers and provided a computer with needed survey and statistical software, or have contracted for these services with NWTEC and other public health professionals. For the 2001 Tribal BRFSS project, over 80% of all individuals involved were American Indian or Alaska Native.
- Standard questions were adapted to encompass cultural activities, spiritual practices and health services relevant to the tribe.
- Questions were added to meet the health priorities and services of each tribe, such as:
 - Point of access for healthcare (tribal clinic vs. other)
 - Use of or need for specific services, such as Elders programs
 - Participation in cultural activities that support health and wellness, such as sweat lodges, canoe journeys, [cultural relay races](#), etc.

These tribal BRFSS surveys have many benefits including greater underlying trust in tribal public health institutions. Tribal members are more willing to answer a phone call or reply to a survey from the tribe or a trusted partner. Tribes were able to adapt BRFSS methodology to achieve greater survey participation, such as:

- Provide information about the tribal BRFSS at community health centers
- Update tribal phone number registries in person before conducting the survey
- Provide the option for in-person or scheduled interviews
- Call from a trusted and local phone number
- Compensation for participation in the form of gift cards, cash incentives, or project promotional items

In the following examples, questions from a sample tribal BRFSS questionnaire are juxtaposed with a similar question or questions from the 2019 CDC BRFSS questionnaire (CDC, 2019). The tribal BRFSS questions contain wording and/or potential responses that provide additional context.

Figure 7: Barriers to Care: Sample Tribal BRFSS and CDC BRFSS Questions

<i>Tribal BRFSS</i>	<i>CDC BRFSS:</i>
<p>Now, I am going to ask you about medical care. When I say ‘medical care,’ I mean physical exams and lab tests.</p> <p>6.6. Was there a time in the last 6 months when you needed medical care and didn’t get it?</p> <p>1 YES 2 NO GO TO Q6.8 7 DON’T KNOW/NOT SURE GO TO Q6.8 9 REFUSED GO TO Q6.8</p> <p>6.7. What were the main reasons you went without needed medical care?</p> <p>01 IT COST TOO MUCH 02 I DIDN’T HAVE INSURANCE 03 THE DOCTOR WOULDN’T TAKE MY INSURANCE 04 I OWED MONEY TO THE CARE PROVIDER 05 I COULDN’T GET AN APPOINTMENT QUICKLY ENOUGH 06 THE OFFICE WASN’T OPEN WHEN I COULD GET THERE 10 I DIDN’T HAVE A DOCTOR 77 DON’T KNOW/NOT SURE 88 OTHER (SPECIFY) _____ 99 REFUSED</p>	<p>C03.03 Was there a time in the past 12 months when you needed to see a doctor but could not because of cost?</p> <p>1 Yes 2 No 7 Don’t know / Not sure 9 Refused</p>

Figure 8: Treatment for High Blood Pressure: Sample Tribal BRFSS and CDC BRFSS Questions

<i>Tribal BRFSS</i>	<i>CDC BRFSS:</i>																																												
<p>8.1. Have you had your blood pressure taken in the past 12 months?</p> <p>1 YES 2 NO 7 DON’T KNOW/NOT SURE 9 REFUSED</p> <p>8.2. Have you ever been told by a health provider that you had high blood pressure? [read only if necessary]: not including high blood pressure while pregnant.</p> <p>1 YES 2 NO GO TO NEXT SECTION 7 DON’T KNOW/NOT SURE GO TO NEXT SECTION 9 REFUSED GO TO NEXT SECTION</p> <p>Now, I AM GOING TO READ A LIST OF REMEDIES YOU MAY BE USING TO TREAT YOUR HIGH BLOOD PRESSURE.</p> <p>8.3. Are you using...</p> <table border="1"> <thead> <tr> <th colspan="2">READ CHOICES</th> <th>YES</th> <th>NO</th> </tr> </thead> <tbody> <tr> <td>A.</td> <td>ORAL MEDICINE (MEDICINE YOU TAKE BY MOUTH)</td> <td>1</td> <td>2</td> </tr> <tr> <td>B.</td> <td>TRADITIONAL MEDICINE (PLEASE DESCRIBE) _____</td> <td>1</td> <td>2</td> </tr> <tr> <td>C.</td> <td>ACUPUNCTURE</td> <td>1</td> <td>2</td> </tr> <tr> <td>D.</td> <td>MASSAGE THERAPY</td> <td>1</td> <td>2</td> </tr> <tr> <td>E.</td> <td>DIET</td> <td>1</td> <td>2</td> </tr> <tr> <td>F.</td> <td>EXERCISE</td> <td>1</td> <td>2</td> </tr> <tr> <td>G.</td> <td>YOGA</td> <td>1</td> <td>2</td> </tr> <tr> <td>H.</td> <td>LIFESTYLE & WELLNESS COACH</td> <td>1</td> <td>2</td> </tr> <tr> <td>I.</td> <td>NO LONGER HAVE HIGH BLOOD PRESSURE</td> <td>1</td> <td>2</td> </tr> <tr> <td>J.</td> <td>OTHER (SPECIFY): _____</td> <td>1</td> <td>2</td> </tr> </tbody> </table>	READ CHOICES		YES	NO	A.	ORAL MEDICINE (MEDICINE YOU TAKE BY MOUTH)	1	2	B.	TRADITIONAL MEDICINE (PLEASE DESCRIBE) _____	1	2	C.	ACUPUNCTURE	1	2	D.	MASSAGE THERAPY	1	2	E.	DIET	1	2	F.	EXERCISE	1	2	G.	YOGA	1	2	H.	LIFESTYLE & WELLNESS COACH	1	2	I.	NO LONGER HAVE HIGH BLOOD PRESSURE	1	2	J.	OTHER (SPECIFY): _____	1	2	<p>C04.01 Have you ever been told by a doctor, nurse, or other health professional that you have high blood pressure?</p> <p>1 Yes 2 Yes, but female told only during pregnancy 3 No 4 Told borderline high or prehypertensive 7 Don’t know / Not sure 9 Refused</p> <p>C04.02 Are you currently taking prescription medicine for your high blood pressure?</p> <p>S 1 Yes 2 No 7 Don’t know / Not sure 9 Refused</p>
READ CHOICES		YES	NO																																										
A.	ORAL MEDICINE (MEDICINE YOU TAKE BY MOUTH)	1	2																																										
B.	TRADITIONAL MEDICINE (PLEASE DESCRIBE) _____	1	2																																										
C.	ACUPUNCTURE	1	2																																										
D.	MASSAGE THERAPY	1	2																																										
E.	DIET	1	2																																										
F.	EXERCISE	1	2																																										
G.	YOGA	1	2																																										
H.	LIFESTYLE & WELLNESS COACH	1	2																																										
I.	NO LONGER HAVE HIGH BLOOD PRESSURE	1	2																																										
J.	OTHER (SPECIFY): _____	1	2																																										

Figure 9. Reasons for Not Exercising: Sample Tribal BRFSS Question

In the example to the right, the tribal BRFSS asks about reasons for not exercising. The 2019 CDC BRFSS has no analogous question.

7.4. What is the **MOST** important reason why you did not exercise in the past month?

01	NOT ENOUGH TIME
02	NOT MOTIVATED, LAZY
03	PHYSICALLY UNABLE
04	DO NOT LIKE TO EXERCISE
05	DO NOT BELIEVE IN BENEFITS OF EXERCISE
06	GET ADEQUATE EXERCISE ON JOB OR FROM DAILY ACTIVITIES
08	LACK OF EXERCISE FACILITIES
10	WEATHER
11	OTHER (SPECIFY) _____
77	DON'T KNOW/ NOT SURE
99	REFUSED

A publicly-available report of six de-identified [tribal BRFSS results](#) (NPAIHB, 2003) elucidates issues that affect Northwest AI/AN communities as a whole while providing tribe-specific information that allows for more targeted health programs and policy-making. Conducting tribal BRFSS surveys allowed tribes to identify key issues specific to each individual tribe.

For example, Figure 10 shows the percent of respondents who received blood cholesterol testing differs widely from tribe to tribe and provides important context for whether a respondent has been told they have high blood pressure.

Figure 10. Tribal BRFSS Data Examples: Cholesterol

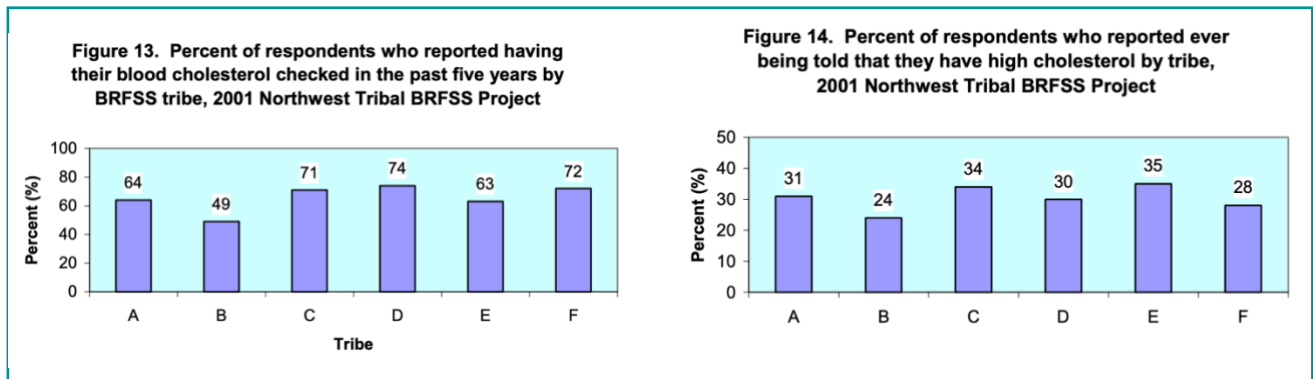


Figure 11. Tribal BRFSS Data Example: Arthritis

Some tribes found higher than expected rates of arthritis and skin cancer and were able to develop relevant programs.

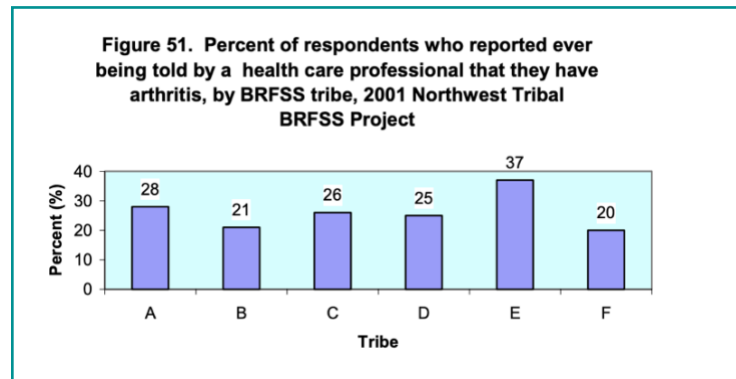
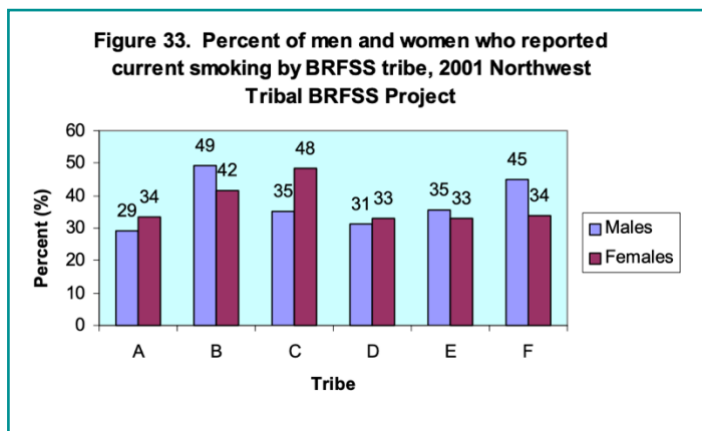


Figure 12. Tribal BRFSS Data Example: Current Smoking



The patterns of tobacco use are also not uniform across tribes, necessitating different strategies to best meet the needs of the community.

The 2003 tribal BRFSS report highlighted the limitations of these efforts:

- Small numbers in small populations can result in inflated estimates.
- In order to attain meaningful sample sizes, tribal BRFSS results were not strictly randomly sampled. Data was not statistically weighted.
- Amount of funding available may affect sample size.

The tribal BRFSS projects provided tribes with relevant and actionable data about the needs of their population. With this information tribes were able to better understand the types of care accessed by tribal members and barriers to that care. The Tribal BRFSS Project unveiled previously unknown public health needs, such as high rates of skin cancer and arthritis, and allowed tribes to develop targeted programs to address these needs. Support from Oregon state in funding tribal BRFSS surveys would allow tribes to continue these meaningful data collection efforts and better serve tribal members.

Literature and Data Use Review

Tribes are wary of data on AI/AN people being incorrectly understood or taken out of context, whether maliciously or unintentionally, when data are interpreted and reported by entities working outside of tribal contexts. This includes data reported by local and state public health agencies.

“How [is OHA] going to control the interpretation of race stratifications, because it is a publicly accessible document? How will the data be protected so it isn’t manipulated by outside parties?”

Tribal Workgroup Member

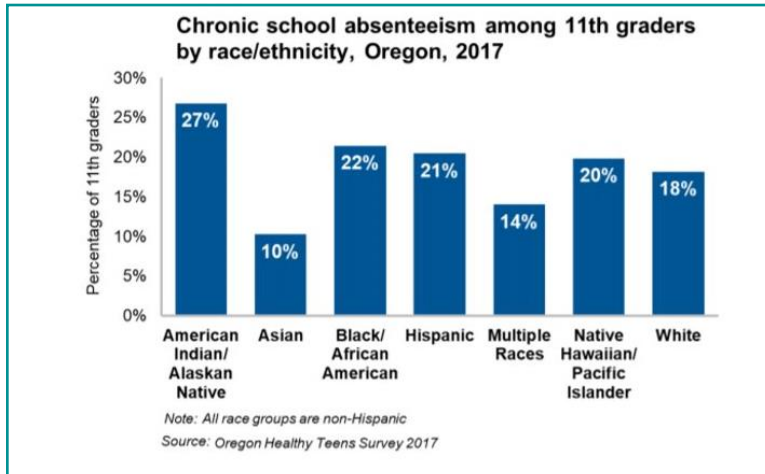
The workgroup was interested in how publicly-available BRFSS and OHT data have been used in the past, and how data has been interpreted. The NPAIHB project team reviewed data reports publicly available on OHA’s website and conducted a literature review. Initially, we investigated publicly-available BRFSS and OHT data by performing an abbreviated independent search and review. We followed this with a request to CDC for a more thorough literature search. CDC conducted a literature search on five databases including Ovid (Medline and Embase), CINAHL, Scopus, and Sociological Abstracts. Search terms were modified for each database to capture articles that mentioned AI/AN BRFSS or OHT data in Idaho, Oregon, or Washington. CDC eliminated duplicate articles and sent NPAIHB a list of citations. As the project team reviewed the results, we excluded dissertations and articles that were captured using the search terms but did not directly address the requested subject matter.

OHA Data Use in Publications

In reviewing the OHA website for examples of how BRFSS and OHT data are reference in state publications and reports, two of the primary documents we explored were the State Health Assessment ([SHA](#)) and State Health Improvement Plan ([SHIP](#)). Oregon’s SHA is updated every five years and provides important information for the development of the SHIP, which is Oregon’s “five-year plan that identifies the state’s health priorities with strategies to advance improvement and measures to monitor progress.”

Lack of meaningful context when presenting comparisons across race groups perpetuates negative stereotypes and fails to address underlying causes of observed disparities. The OHA Social Determinants of Health Report (2019) on [Chronic School Absenteeism](#) discusses the relationship between high absenteeism and long-term academic challenges. Using 2017 OHA data, the report compares students with high and low absenteeism along A/B grades, depression in the past year, fair/poor physical and mental health and compares absenteeism across race. AI/AN 11th graders had the highest percent absenteeism at 27%.

Figure 13: Chronic School Absenteeism (OHA)



The OHA report states that “an array of social determinants can be barriers to students being in school, including poor health, poverty, transportation, and other familial and community factors,” but does not provide context or examples for how these factors may disproportionately affect 11th grade student absenteeism among AI/AN students, such as the need for

11th graders to work to support themselves financially or the need to care for younger family members. Some of the tribal workgroup members have worked extensively with student populations and were able to provide more context around student absenteeism. In addition to social determinants, AI/AN students report missing school days due to cultural activities, ranging from dance performances to ceremonies that may last many days.

External Peer Reviewed Manuscripts

The results of the literature review yielded a variety of papers and topics, ranging from minority health surveillance reports to specific AI/AN determinants of health. We grouped the manuscripts into the following categories:

- General health surveillance (4)
- Cowlitz Tribal BRFSS results (1)
- Multiracial grouping (2)
- AI/AN-focused research (4)
- Research with no primary focus or results on AI/AN communities (4)

Two of the papers identified discussed the importance of multi-race ethnicity analyses in BRFSS. Bratter et al. (2018), found that the best race methodology has the potential to obscure health disparities when multiracial respondents identify with single-race groups. The authors found this to be particularly relevant for multiracial white AI/AN respondents who reported white as their best race while experiencing a greater number of health disadvantages than single-race white respondents. The importance of multi-race groups was exemplified by Asdigian et al. (2018) in comparison of AI/AN mental health burden estimates when using single and multi-race methods. In particular, the authors found that multi-race AI/AN respondents experienced a higher lifetime prevalence of diagnosed depressive disorder and frequent poor mental health and mental distress than both the single-race white group and single-race AI/AN group.

Together these studies highlight some of the substantial issues with best-race consolidation and the ways in which this method has the potential to drastically skew results.

Four of the manuscripts covered general health surveillance and four manuscripts were not primarily focused on AI/AN communities. Descriptions of these articles are available in Appendix A. A number of the manuscripts identified in the literature review discussed stigmatizing topics such as adverse childhood events and the effect of tribal casinos on tribal health. The NPAIHB project team was able to identify multiple co-authors who identify as AI/AN or who work closely with tribal organizations, but further research would be needed to establish what proportion of these articles were affiliated with tribal organizations. While we understand that OHA maintains data request and access records, maintaining resources for tracking who tribal data were released to and whether or not that group is affiliated with a tribe or tribal organization is essential to understanding how this data is distributed and how OHA is ensuring tribal data sovereignty is protected.

Recommendations

NPAIHB is grateful for the opportunity to convene a tribal workgroup to provide feedback to OHA on the current usefulness of the BRFSS and OHT survey data for AI/AN communities. However, we recognize that the project had numerous limitations (see pages 13-14), and we caution against considering this report to be comprehensive. The findings in this report should instead be taken as preliminary observations that require further exploration and investment.

As a summary of the discussion and suggestions by the tribal workgroup, we would like to offer the following recommendations to the Oregon Health Authority:

Actionable Data

- Localized tribal-specific data is preferable and more useful than state-wide or county-wide data.
- Incorporate non-Western approaches to health and healthcare (traditional healing, etc.) into BRFSS and OHT survey questions.

Survey Methods

- Partner with tribes and tribal or urban AI/AN organizations to increase BRFSS participation and educate community members about the BRFSS and OHT. Provide community members with information on who is collecting the data and for what purpose, and why their participation is important.
- Include questions on protective factors, particularly those that may come from involvement in tribal and AI/AN community activities.

Tribal and AI/AN Community Engagement

- Support Oregon tribes in conducting tribal BRFSS surveys. Further outreach and discussion are needed to determine specific tribal needs and make detailed recommendations.
- Protect tribal data and tribal sovereignty. Consider instituting requirements for researchers and others not affiliated with tribes or tribal/urban AI/AN organizations, who want to access and use AI/AN data held by the state. OHA should track how AI/AN data are used, where data analyses or reports are posted or published, and ensure tribal and AI/AN community oversight and transparency.
- Work with Oregon tribes, NARA-NW and other urban AI/AN organizations, and the NWTEC to convene future discussions with health program staff, tribal leaders, and other stakeholders to better understand data needs and priorities.

Next Steps

- Seek additional feedback and input from tribes and AI/AN organizations, both from leadership and community members, on how to improve BRFSS and OHT data quality and useability. While the 2021 workgroup process was an important step, much work remains to be done, and much more conversation is needed.
- Continued long-term engagement with AI/AN communities is critical to ensure that the initial recommendations in this report can be refined and expanded. OHA should utilize existing forums and recurring tribal meetings to further discuss survey modernization, but also consider holding listening sessions hosted by and within tribal and AI/AN communities.

References

- Bureau of Indian Affairs. (n.d.) *Frequently Asked Questions: Who is an American Indian or Alaska Native?* Retrieved July 2021 from <https://www.bia.gov/frequently-asked-questions>
- Centers for Disease Control and Prevention. (n.d.) *2019 BRFSS Questionnaire*. Retrieved June 2021 from <https://www.cdc.gov/brfss/questionnaires/pdf-ques/2019-BRFSS-Questionnaire-508.pdf>
- Coalition of Communities of Color & Portland State University. (n.d.). *The Native American Community in Multnomah County: An Unsettling Profile*. <https://www.portlandoregon.gov/civic/article/505489>
- Confederated Tribes of Siletz Indians. (n.d.) *Gallery V – Run to the Rogue*. <http://www.ctsi.nsn.us/chinook-indian-tribe-siletz-heritage/salishan-nehalem-warm-springs-siletz-photos/gallery-v---run-to-the-rogue#content>
- Haozous, E. A., Strickland, C. J., Palacios, J. F., & Solomon, T. G. A. (2014). Blood politics, ethnic identity, and racial misclassification among American Indians and Alaska Natives. *Journal of Environmental and Public Health*. <https://www.hindawi.com/journals/jep/2014/321604/>
- Indian Health Service. (n.d.). *Requirements: Purchased/Referred Care [PRC] Delivery Areas*. Retrieved June 2021 from <https://www.ihs.gov/prc/eligibility/requirements-purchased-referred-care-prc-delivery-areas/>
- Jim, M. A., Arias, E., Seneca, D. S., Hoopes, M. J., Jim, C. C., Johnson, N. J., & Wiggins, C. L. (2014). Racial misclassification of American Indians and Alaska Natives by Indian Health Service contract health service delivery area. *American Journal of Public Health, 104*(S3), S295-S302. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4035863/pdf/AJPH.2014.301933.pdf>
- Maly, A. G., et al. (2014). Colorectal cancer screening among American Indians in a Pacific Northwest tribe: Cowlitz tribal BRFSS project, 2009-2010. *Public Health Reports 129*(3): 280-288. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3982554/>
- Northwest Portland Area Indian Health Board. (2021). *Improving Data & Enhancing Access – Northwest (IDEA-NW) Project*. <https://www.npaihb.org/idea-nw>
- Northwest Portland Area Indian Health Board. (2003). *Northwest Tribal Behavioral Risk Factor Surveillance System (BRFSS) Project*. <https://docplayer.net/62077647-Northwest-tribal-behavioral-risk-factor-surveillance-system-brfss-project-aggregate-final-report.html>

- NPC Research. (n.d.). *Oregon Native American Youth Survey*. Retrieved June 2021 from https://npcresearch.com/wp-content/uploads/ONYS_NEW.pdf
- Oregon Health Authority. (2020). *Healthier Together Oregon: 2020-2024 State Health Improvement Plan*. https://healthiertogetheroregon.org/wp-content/uploads/2020/08/Healthier-Together-Oregon_fullplan-1.pdf
- Oregon Health Authority. (2018). *Oregon's State Health Assessment*. <https://www.oregon.gov/oha/PH/ABOUT/Documents/sha/state-health-assessment-full-report.pdf>
- Oregon Health Authority. (n.d.). *Social Determinants of Health: Chronic School Absenteeism*. Retrieved June 2021 from <https://www.oregon.gov/oha/PH/ABOUT/Documents/indicators/absenteeism.pdf>
- Oregon Health Authority Tribal Affairs (2018). *Tribal Consultation and Urban Indian Health Program Confer Policy*. https://www.oregon.gov/oha/documents/Tribal_Consultation_and_UIHP_Confer_Policy.pdf
- TribalEpiCenters.org (2021). *History*. <https://tribalepicenters.org/history/>
- US Census Bureau. (2019) *ACS 5-Year Estimates Data Profiles: Oregon*. <https://data.census.gov/cedsci/table?g=0400000US41&tid=ACSDP5Y2019.DP05>
- US Census Bureau. (2019) *ACS 5-Year Estimates Data Profiles: Portland-Vancouver-Hillsboro, OR-WA Metro Area*. <https://data.census.gov/cedsci/table?tid=ACSDP5Y2019.DP05&g=310M500US38900>
- US Census Bureau. (2019) *ACS 5-Year Estimates Data Profiles: Salem, OR Metro Area*. <https://data.census.gov/cedsci/table?tid=ACSDP1Y2019.DP05&g=310M500US41420>
- US Census Bureau. (2019) *ACS 5-Year Estimates Data Profiles: Salem, OR Metro Area*. <https://data.census.gov/cedsci/table?tid=ACSDP5Y2019.DP05&g=310M500US21660>
- US Census Bureau. (2019) *ACS 5-Year Estimates Data Profiles: Salem, OR Metro Area*. <https://data.census.gov/cedsci/table?tid=ACSDP5Y2019.DP05&g=310M500US32780>
- US Census Bureau. (2019) *ACS 5-Year Estimates Data Profiles: Salem, OR Metro Area*. <https://data.census.gov/cedsci/table?tid=ACSDP5Y2019.DP05&g=310M500US10540>
- US Census Bureau. (2019) *ACS 5-Year Estimates Data Profiles: Salem, OR Metro Area*. <https://data.census.gov/cedsci/table?tid=ACSDP5Y2019.DP05&g=310M500US13460>

Appendix A

Literature Review Results

Tribal BRFSS

Maly, A.G., Steel, T.L., Fu, R., Lieberman, D.A., & Becker, T.M. (2014). "Colorectal cancer screening among American Indians in a Pacific Northwest tribe: Cowlitz tribal BRFSS project, 2009-2010." *Public Health Reports* 129(3): 280-288.
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3982554/>

Compares tribal BRFSS results to NHW BRFSS results to find that Cowlitz tribal members are receiving CRC screenings at the same rate as NHW, despite lower socioeconomic status. Attributes the lack of disparity to the tribe's Colon Health Program and encourages further investment.

Multiple Race Groupings

Asdigian, N.L., Running Bear, U., Beals, J., Manson, S.M., & Kaufman, C.E. (2018). "Mental health burden in a national sample of American Indian and Alaska Native adults: Differences between multiple-race and single-race subgroups." *Social Psychiatry and Psychiatric Epidemiology* 53(5):521-530. <https://link.springer.com/article/10.1007%2Fs00127-018-1494-1>

Authors find that multi-race AI/AN BRFSS respondents report worse mental health burden than single-race AI/AN or single-race NHW. Discusses limitations and issues surrounding single-race classification.

Bratter, J.L., & Gorman, B.K. (2011). "Does multiracial matter? A study of racial disparities in self-rated health." *Demography* 48(1): 127-152.
<https://link.springer.com/article/10.1007/s13524-010-0005-0>

Authors find that placing multi-race respondents into single-race groupings can obscure health disparities between non-White and NHW respondents. This pattern was most apparent among AI/AN respondents who identified white as their best race while facing greater health disadvantages than single-race White respondents.

Elders

Goins, R.T., John, R., Hagan Hennessy, C., Denny, C.H., & Buchwald, D. (2006). "Determinants of Health-Related Quality of Life among Older American Indians and Alaska Natives." *Journal of Applied Gerontology* 25(1 supplement): 73S-88S.
<https://journals.sagepub.com/doi/abs/10.1177/0733464805283037>

Found that AI/AN elders had a lower health-related quality of life (HRQoL) than the general population, with more than 1/3 of AI/AN elders report fair or poor self-rated

health. Age, education, income, employment, hypertension and obesity were also associated with HQRoL indicators.

Family Planning

Volscho, T.W. (2011). "Racism and Disparities in Women's Use of the Depo-Provera Injection in the Contemporary USA." *Critical Sociology* 37(5): 673-688.
<https://journals.sagepub.com/doi/10.1177/0896920510380948>

Discusses current rates of Depo-Provera use among Black and AI/AN women in the context of racial sterilization abuse in the 1960-70s.

Mental Health

Giano, Z., Camplain, R. L., Camplain, C., Pro, G., Haberstroh, S., Baldwin, J. A., Wheeler, D.L., & Hubach, R. D. (2021). Adverse Childhood Events in American Indian/Alaska Native Populations. *American Journal of Preventive Medicine* 60(2), 213-221.
<https://www.sciencedirect.com/science/article/abs/pii/S0749379720304050>

AI/AN respondents had higher ACEs scores than White, Black and Hispanic respondents. Women, those who are younger and have lower income, and sexual minorities reported higher ACEs score.

Tribal Casinos

Wolfe, B., Jakubowski, J., Haveman, R., & Courey, M. (2012). "The Income and Health Effects of Tribal Casino Gaming on American Indians." *Demography* 49(2): 499-524.
<https://link.springer.com/content/pdf/10.1007/s13524-012-0098-8.pdf>

Uses BRFSS, tribal-level data, and county-level data to assess the effect of casino gaming on the income and health of tribal members. The authors generate estimates for positive health effects for tribal members.

General Health Surveillance

Liao, Y., Tucker, P., Okoro, C.A, Giles, W.H., Mokdad, A.H., & Bales Harris, V. (2004). "REACH 2010 Surveillance for Health Status in Minority Communities – United States, 2001-2002." *Morbidity & Mortality Weekly Report*. 53(6): 1-36.
<https://www.cdc.gov/mmwr/preview/mmwrhtml/ss5306a1.htm>

Compares REACH and BRFSS results. Among AI/AN, report high levels of obesity, cigarette smoking, cardiovascular disease, hypertension, high blood cholesterol and diabetes.

Liao, Y., Bang, D., Cosgrove, S., Dulin, R., Harris, Z., Stewart, A., Taylor, A., White, S., Yatabe, G., Liburd, L., & Giles, W. (2011). "Surveillance of health status in minority communities – Racial and Ethnic Approaches to Community Health across the U.S. (REACH U.S.) Risk Factor Survey, United States, 2009." *Morbidity & Mortality Weekly Report* 60(SS06): 1-41. <https://www.cdc.gov/mmwr/preview/mmwrhtml/ss6006a1.htm>

Compares REACH and BRFSS results. Among AI/AN, report high levels of obesity, cigarette smoking, reported fair/poor health, hypertension, cardiovascular disease, diabetes and low mammography screening rates.

Towne, S.D. (2017). "Assessing Diabetes and Factors Associated with Foregoing Medical Care among Persons with Diabetes: Disparities Facing American Indian/Alaska Native, Black, Hispanic, Low Income, and Southern Adults in the U.S. (2011–2015)." <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5451915/>

Authors assess rates of diabetes and foregoing medical care by race. AI/AN had one of the highest rates of diabetes through 2011-2015, in addition to high rates of forgone medical care.

Zahran, H. S., Kobau, R., Moriarty, D.G., Zack, M.M., Holt, J., & Donehoo, R. (2005). "Health-related quality of life surveillance--United States, 1993-2002." *Morbidity & Mortality Weekly Report*. 54(4): 1-35. <https://www.cdc.gov/mmwr/preview/mmwrhtml/ss5404a1.htm>

AI/AN reported higher rates of fair/poor health, physically and mentally unhealthy days, activity limitations. The authors attribute disparities to "factors such as income, education, occupation, disease status, behavioral risk factors, social and cultural factors (e.g., disenfranchisement and discrimination)."

Manuscripts not primarily focused on AI/AN respondents

Hahn, R., et al. (2000). "Health Risk Aversion, Health Risk Affinity, and Socio-Economic Position in the USA: The Demographics of Multiple Risk." *Health, Risk & Society* 2(3): 295-314. <https://www.tandfonline.com/doi/abs/10.1080/713670164>

Compares behavioral risk factors by race, including: smoking, heavy drinking, overweight, seatbelt use, vaccination and Pap smear, mammography and colorectal screening. Authors report that AI/AN and Black respondents had lower than expected prevalence of low risk factors and higher than expected prevalence of high-risk factors.

Kim, D., Subramanian, S.V., Gortmaker, S.L., & Kawachi, I. (2006). "US State-and County-Level Social Capital in Relation to Obesity and Physical Inactivity: A Multilevel, Multivariable Analysis." *Social Science & Medicine* 63(4): 1045-1059. <https://www.sciencedirect.com/science/article/abs/pii/S0277953606001080>

Examines the relationship between social capital and physical health, finding low efficacy of social capital on obesity among AI/AN. The authors attribute the lack of a relationship among AI/AN to high obesity rates and “the possible presence of much fewer social interactions with the general population (e.g., due to cultural/ethnic divides or, for some individuals, physical separation through residence on reservations) might also explain the relative inefficacy among them of social capital levels present in the general population.”

Johnson, D.A., Jackson, C.L., Williams, N.J., & Alcantara, C. (2019). “Are sleep patterns influenced by race/ethnicity – a marker of relative advantage or disadvantage? Evidence to date.” *Nature and Science of Sleep* 11: 79-95.
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6664254/pdf/nss-11-79.pdf>

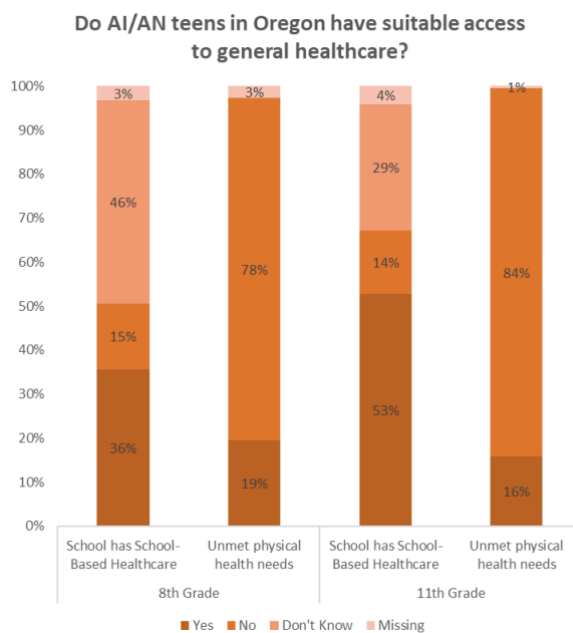
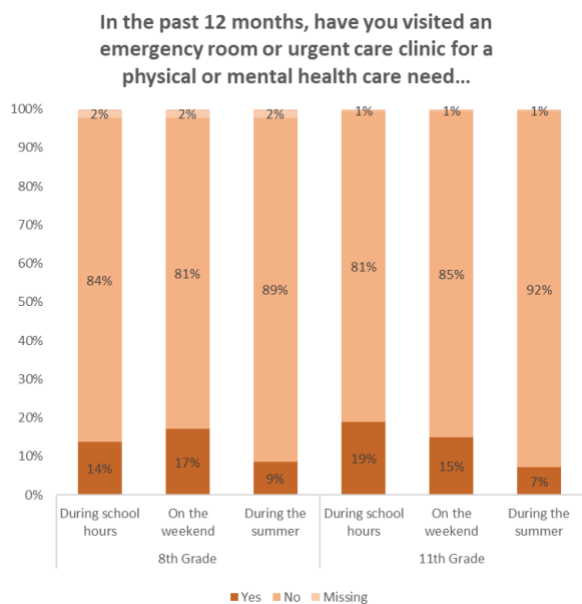
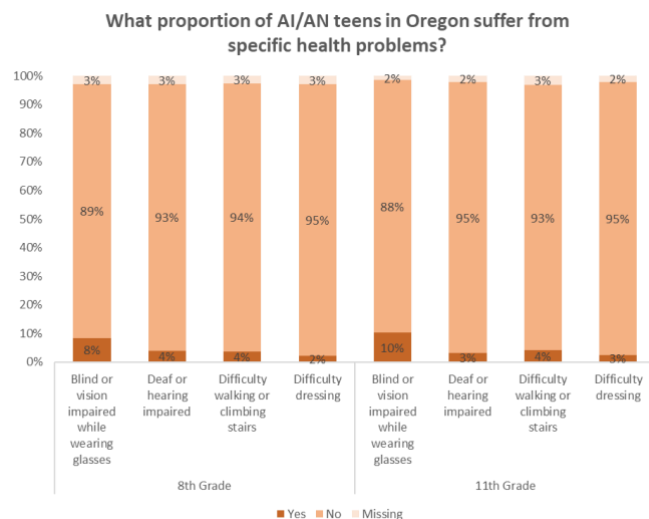
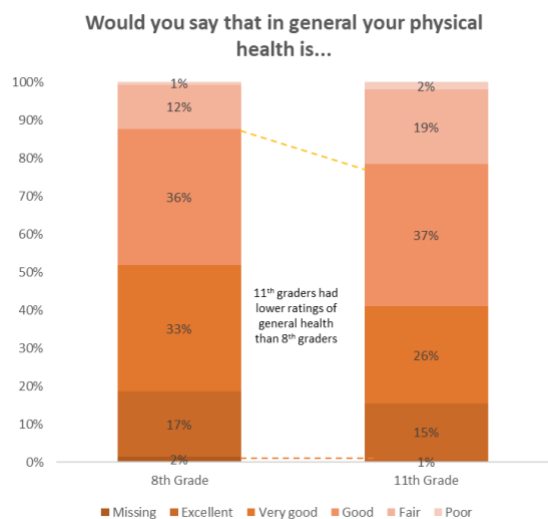
Discusses sleep duration by race and ethnicity. Authors find that AI/AN respondents had a lower age-adjusted prevalence of healthy sleep and higher levels of insufficient sleep.

Tuthill, Z., Denney, J.T., & Gorman, B. (2020). "Racial disparities in health and health behaviors among gay, lesbian, bisexual and heterosexual men and women in the BRFSS-SOP." *Ethnicity and Health* 25(2): 177-188.
<https://www.tandfonline.com/doi/full/10.1080/13557858.2017.1414157>

The report examines health and health behaviors among sexual minorities. Among AI/AN, bisexuals had lower odds of obesity than heterosexuals.

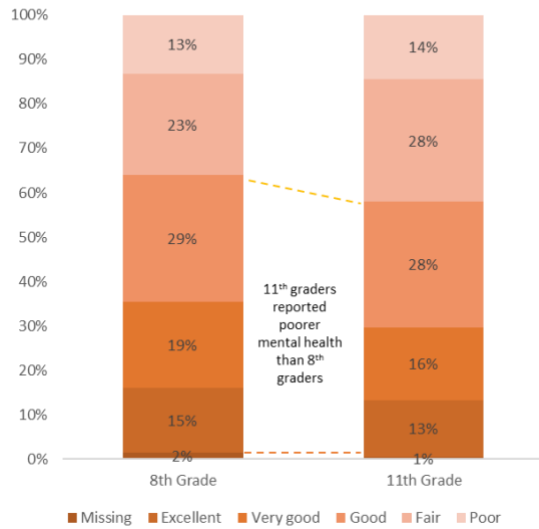
Appendix B Requested Data Analyses

How is the general health of AI/AN teens in Oregon?

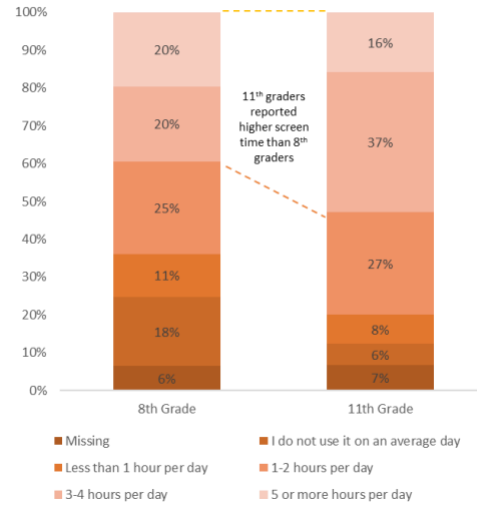


How is the mental health of the AI/AN teens in Oregon?

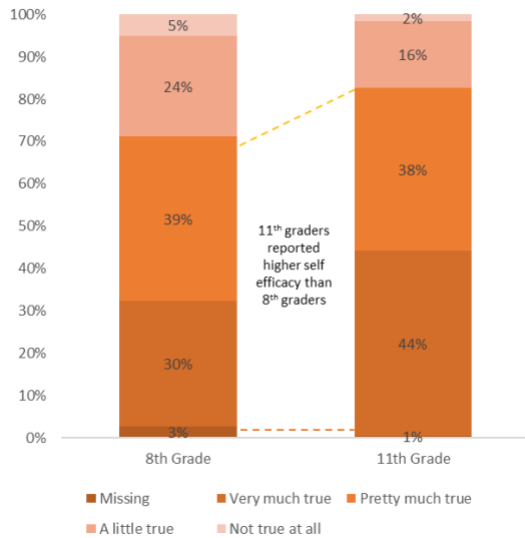
Would you say that in general your emotional and mental health is...



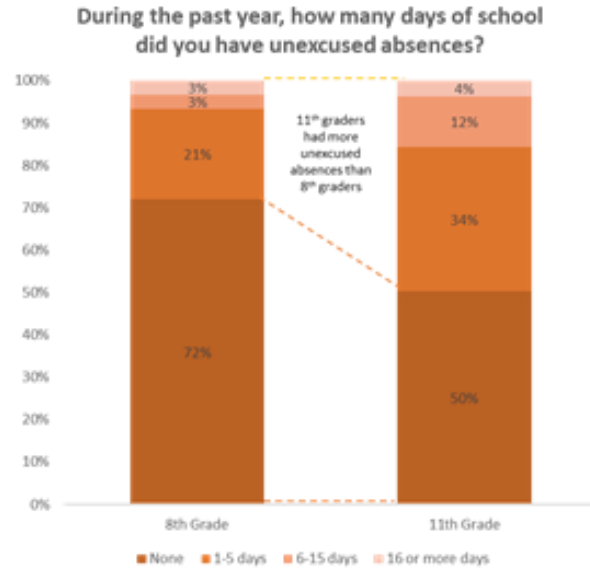
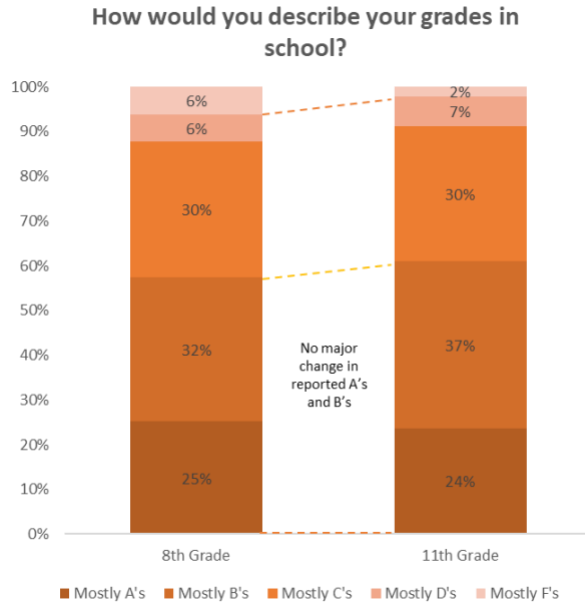
On an average day, how many hours do you use social media?



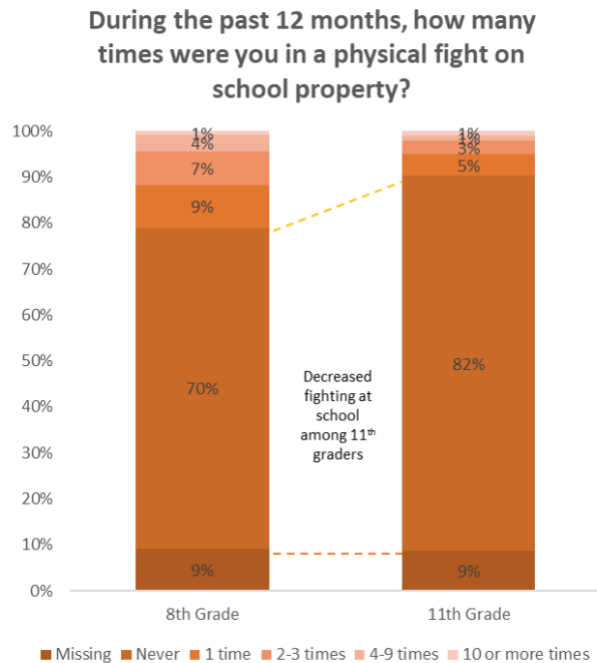
I can work out my problems.



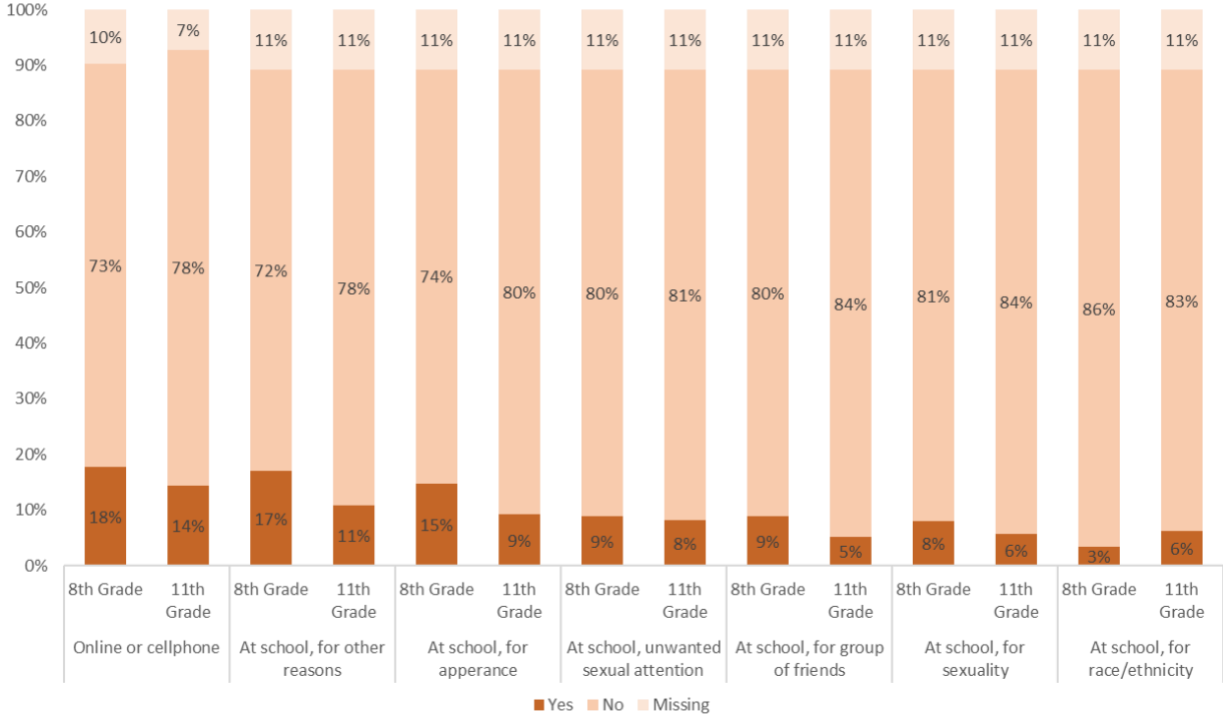
How are AI/AN teens performing at school?



To what extent do the schools that AI/AN teens attend in Oregon feature harmful, dangerous, or criminal behavior?

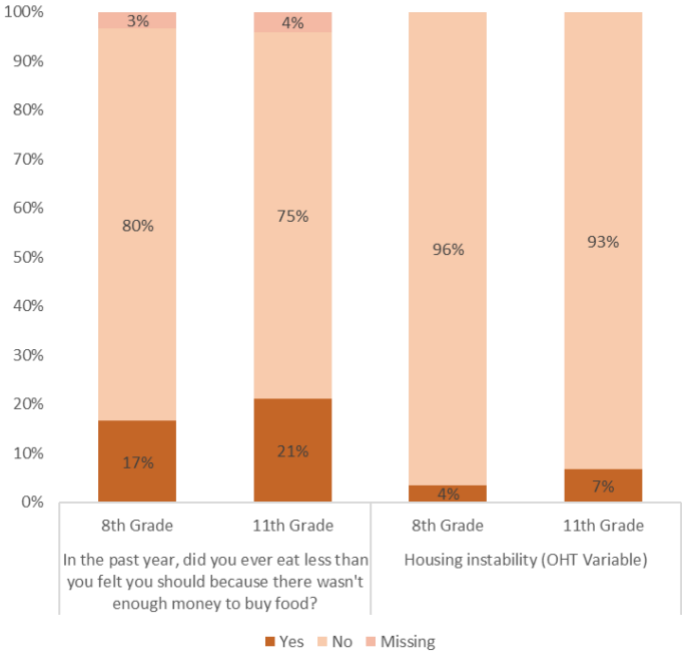


Experiences of Bullying

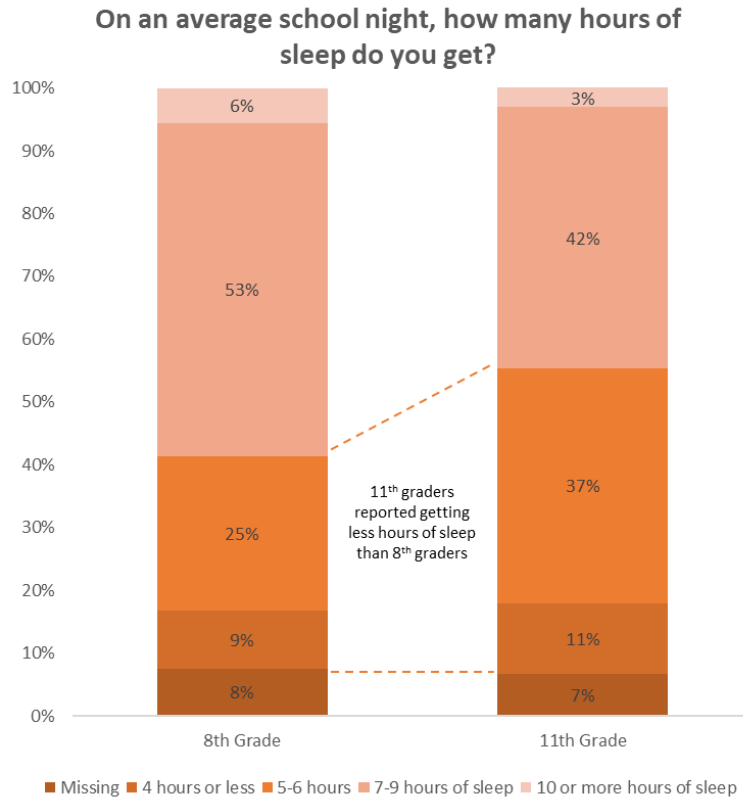


To what extent do AI/AN teens in Oregon suffer from money concerns?

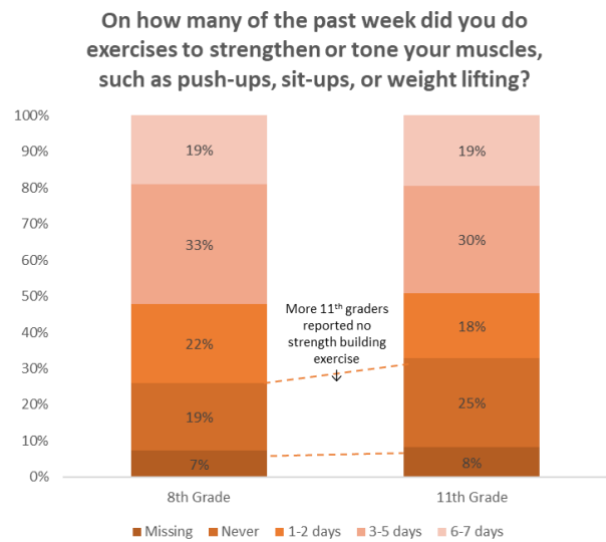
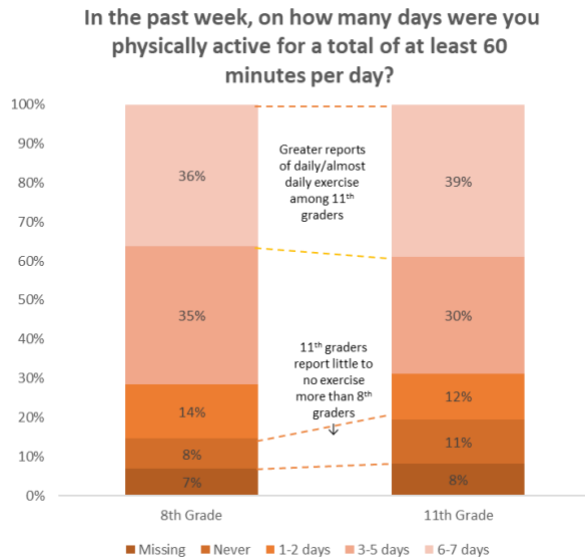
Economic Wellbeing



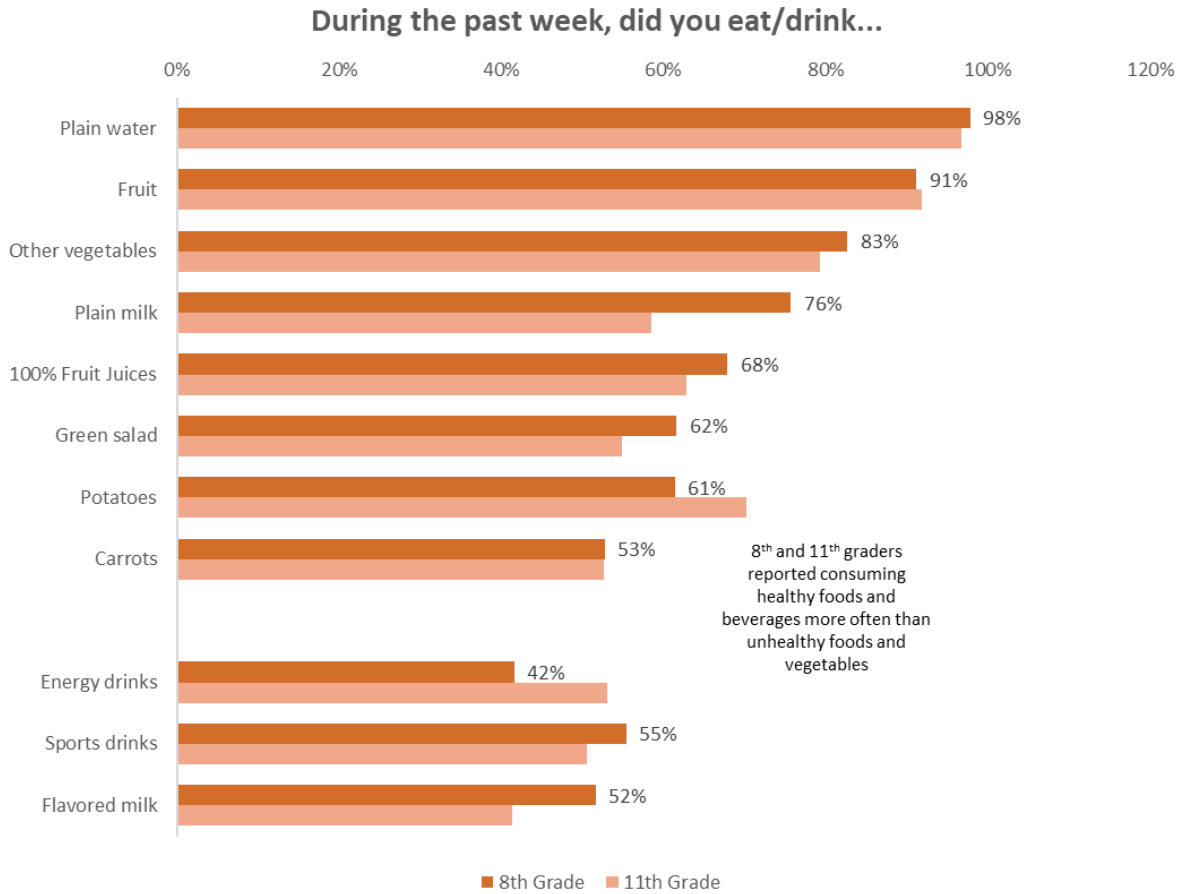
How often do AI/AN teens in Oregon get enough sleep?



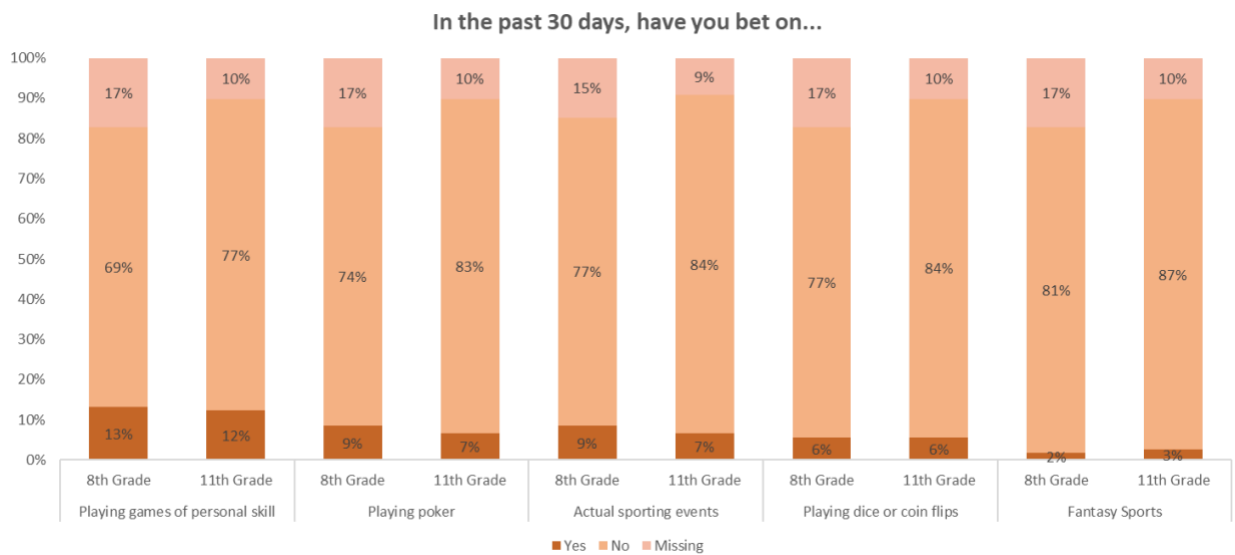
Do AI/AN teens in Oregon get sufficient exercise?



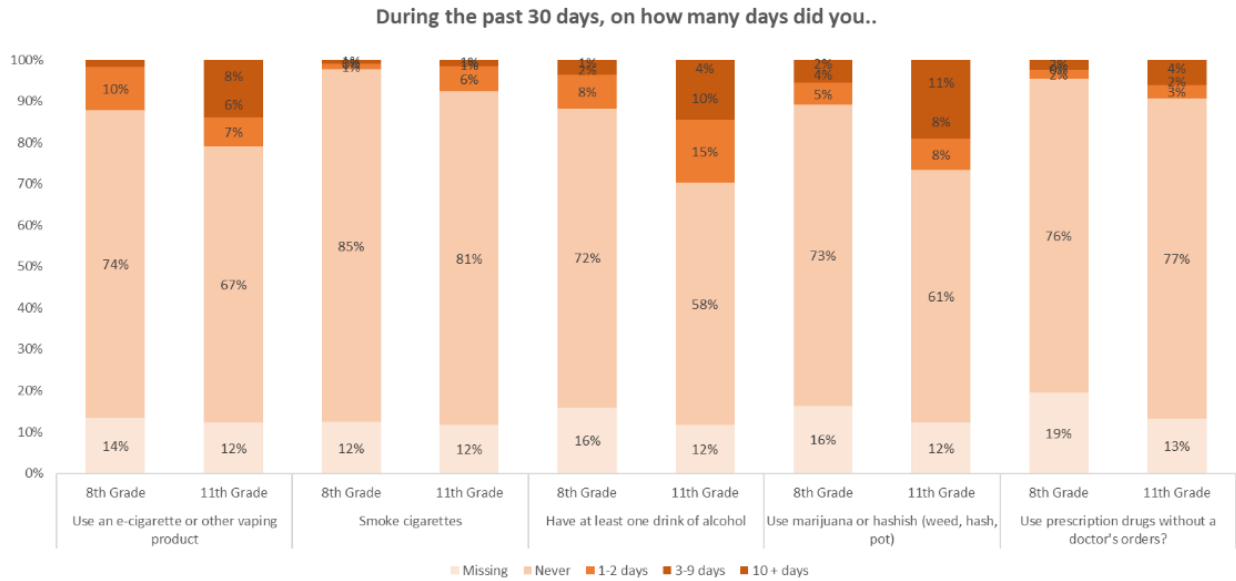
How often do AI/AN teens in Oregon eat healthy foods?



To what extent do AI/AN teens in Oregon engage in risky or harmful behavior?



To what extent do AI/AN teens in Oregon use legal and illegal drugs?



To what extent do AI/AN teens in Oregon experience abuse?

