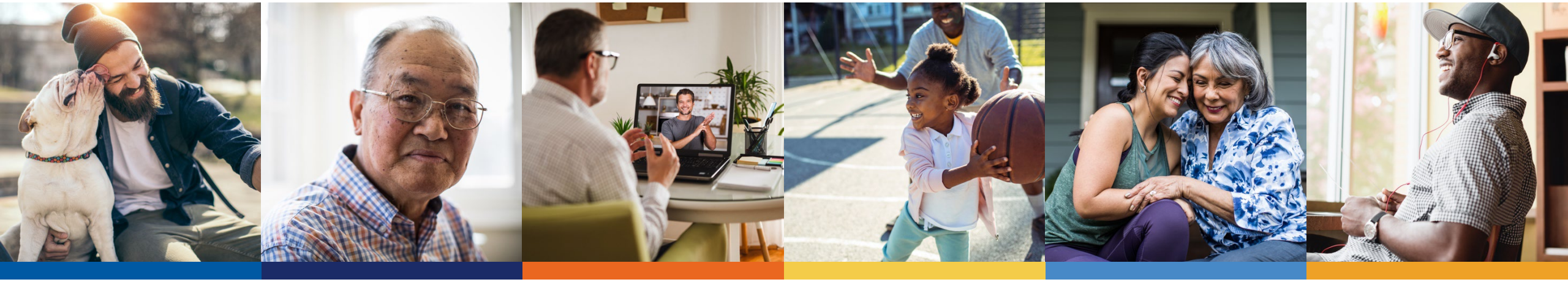
W O R K I N G T O A C H I E V E H E A L T H E Q U I T Y



Health Equity Update from CMS Office of Minority Health

September 25, 2023

Meagan Khau
Data Analytics & Research Group
CMS Office of Minority Health

CMS
CENTERS FOR MEDICARE & MEDICAID SERVICES
OFFICE OF MINORITY HEALTH

CMS OMH Overview

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CMS Office of Minority Health

The Centers for Medicare & Medicaid Services (CMS) is the largest provider of health insurance in the United States, responsible for ensuring that more than 170 million individuals supported by CMS programs (Medicare, Medicaid, Children's Health Insurance Program, and the Health Insurance Marketplaces) are able to get the care and health coverage they need and deserve.

The Centers for Medicare & Medicaid Services Office of Minority Health (CMS OMH) is one of eight offices of minority health within the U.S. Department of Health and Human Services. CMS OMH works with local and federal partners to eliminate health disparities while improving the health of all minority populations, racial and ethnic communities, people with limited English proficiency, lesbian, gay, bisexual, transgender, and queer (LGBTQ+) persons; persons with disabilities; persons who live in rural areas; and persons otherwise adversely affected by persistent poverty or inequality.

CMS Framework for Health Equity & The Path Forward: Improving Data to Advance Health Equity Solutions

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CMS Framework for Health Equity: 5 Priority Areas

Priority 1: Expand the Collection, Reporting, and Analysis of Standardized Data

Priority 2: Assess Causes of Disparities Within CMS Programs, and Address Inequities in Policies and Operations to Close Gaps

Priority 3: Build Capacity of Health Care Organizations and the Workforce to Reduce Health and Health Care Disparities

Priority 4: Advance Language Access, Health Literacy, and the Provision of Culturally Tailored Services

Priority 5: Increase All Forms of Accessibility to Health Care Services & Coverage

go.cms.gov/omh

CMS Framework for Advancing Health Care in Rural, Tribal, and Geographically Isolated Communities

Priority 1: Apply a Community-Informed Geographic Lens to CMS Programs and Policies

Priority 2: Increase Collection and Use of Standardized Data to Improve Health Care for Rural, Tribal, and Geographically Isolated Communities

Priority 3: Strengthen and Support Health Care Professionals in Rural, Tribal, and Geographically Isolated Communities

Priority 4: Optimize Medical and Communication Technology for Rural, Tribal, and Geographically Isolated Communities

Priority 5: Expand Access to Comprehensive Health Care Coverage, Benefits, and Services and Supports for Individuals in Rural, Tribal, and Geographically Isolated Communities

Priority 6: Drive Innovation and Value-Based Care in Rural, Tribal, and Geographically Isolated Communities

OMH's Data White Paper

- Describes the current state of health equity data collection and consolidation across CMS programs
- Details progress to date
- Defines CMS' future actions to continue the improvement of health equity data and achieve a future vision of health equity data at CMS

https://www.cms.gov/files/document/path-forwardhe-data-paper.pdf

1. Sociodemographic and social determinants/drivers of health (SDOH) health equity data can help drive quality improvement and improve program/policy evaluation

2. Despite progress, there are gaps in the availability, completeness, and quality of health equity data remain across CMS programs

3. CMS is committed to improving the quality, accuracy, and completeness of data that can enable improvements in health equity

4. Efforts to address these health equity-related data issues are already underway and will be prioritized

Completeness, Quality and Accuracy Issues in Enrollee Sociodemographic Data Collection

Sociodemographic Data Type*	Fee-for-Service Medicare**	Medicare Advantage***	Medicaid and CHIP†	Marketplace®‡
Sex	●	●	●	●
Geography	◊	◊	○	◊
Language	○	○	○	○
Disability Status	○	○	○	○
Income	◊	◊	◊	◊
Race/Ethnicity	○	○	○	●
Sexual Orientation and Gender Identity	-	-	-	-

Key:

● Collected aligned to 2011 HHS standards

○ Collected with standards and/or completeness issue(s)

◊ Collected with no major issues, no adopted standard

- Not collected

* The data elements included in this table are the same as those prioritized in Executive Order 13985 and the CMS Framework for Health Equity, and do not encompass all data elements that could be collected or improved.[1,3] This table does not reflect quality and completeness issues in all cases.

** Data received from SSA and collected via surveys detailed in the sections below.

*** Data collected from Medicare Part C/D enrollment form and various surveys detailed in the sections below, supplemented as needed with SSA data from Fee-for-Service Medicare.

† Data reported from states in the Transformed Medicaid Statistical Information System (T-MSIS).

‡ Data collected from the Marketplace programs using Healthcare.gov platform. Because CMS does not closely regulate data collection on State-Based Exchanges, this table shows data collected on the Federally-Facilitated Exchanges only.

Health Equity Data: Progress to Date

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OFFICE OF MINORITY HEALTH

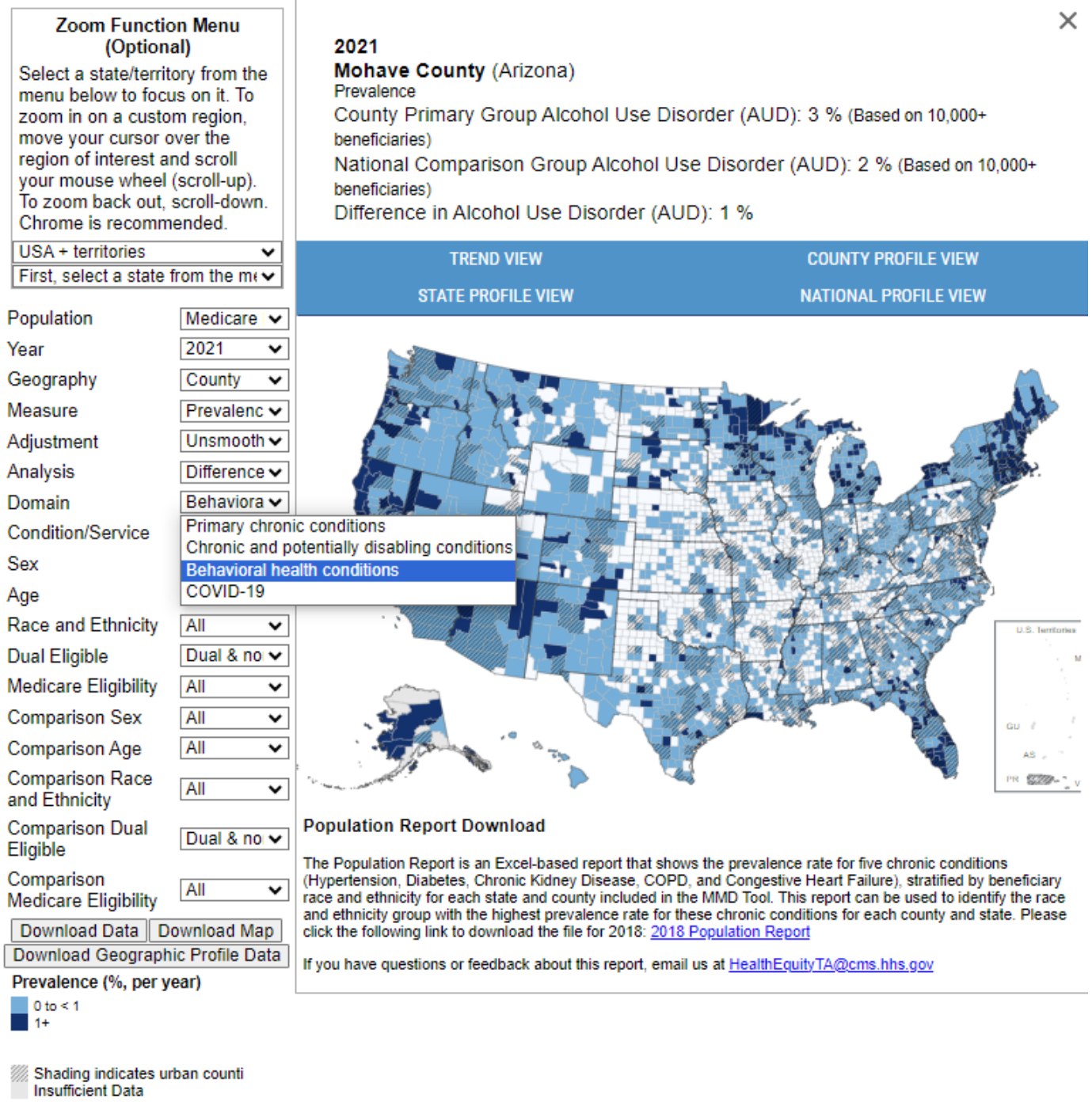
Office of Management and Budget's Revision to the Statistical Standards on Race and Ethnicity

- The Office of the Chief Statistician of the United States took a key step forward in its formal process to revise Office of Management and Budget's (OMB's) statistical standards for collecting and reporting race and ethnicity data across Federal agencies by releasing a set of initial proposals in a Federal Register Notice.
- These were initial proposals developed by an Interagency Technical Working Group – they are not the final recommendations from the Working Group to OMB, and they do not represent the positions of OMB or the agencies participating on the Working Group.
- Comments were due April 27th and more than 20,000 comments were submitted.
- OMB provided that they will release the new standards by Summer 2024.

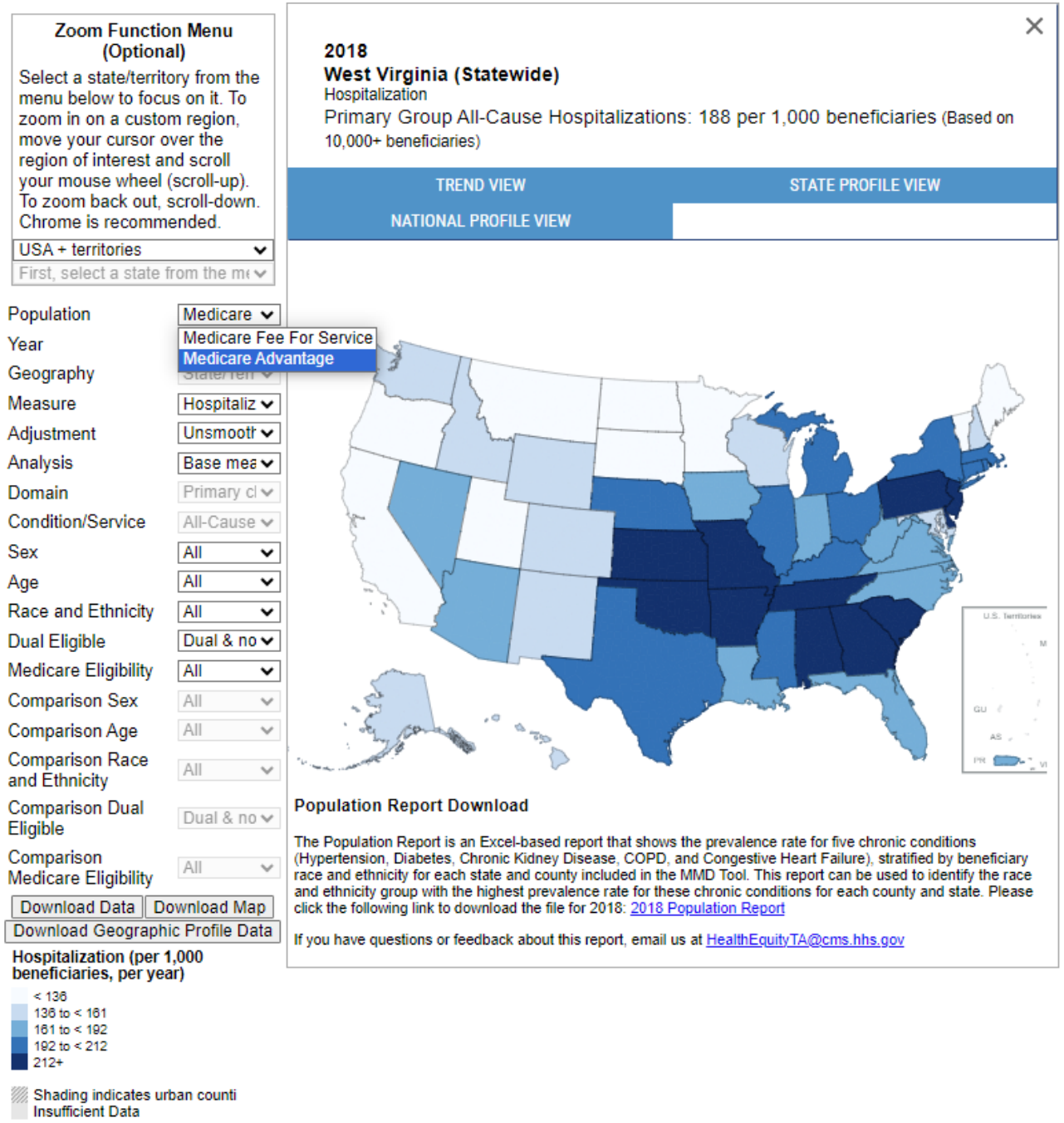
Race & Ethnicity Data Collection at Disaggregated Level

- CMMI Models - Started January 1, 2023 – All CMMI model participants will be required to report race and ethnicity data at the USCDI standards
- Post-Acute Care Settings - Data Collection at the 2011 HHS Data Standards
  - —October 2022 – Started to collect race and ethnicity data in long term care and inpatient rehabilitation facilities.
  - —January 2023 – Started to collect race and ethnicity data in home health agencies.
  - —October 2023 – Will collect race and ethnicity data in skilled nursing facilities.

Mapping Medicare Disparities (MMD) Tool



Mapping Medicare Disparities (MMD) Tool



TDLC Program Overview

The **Tribal Data Learning Community (TDLC)** is a new one-year pilot program for researchers at **Tribal Epidemiology Centers (TECs)** to conduct research that is meaningful to Tribal communities using CMS data.

The TDLC is sponsored by the CMS Office of Minority Health in partnership with the CMS Division of Tribal Affairs.

The goal of the TDLC is to provide participating TECs with resources to assess the needs of their communities and develop appropriate interventions.

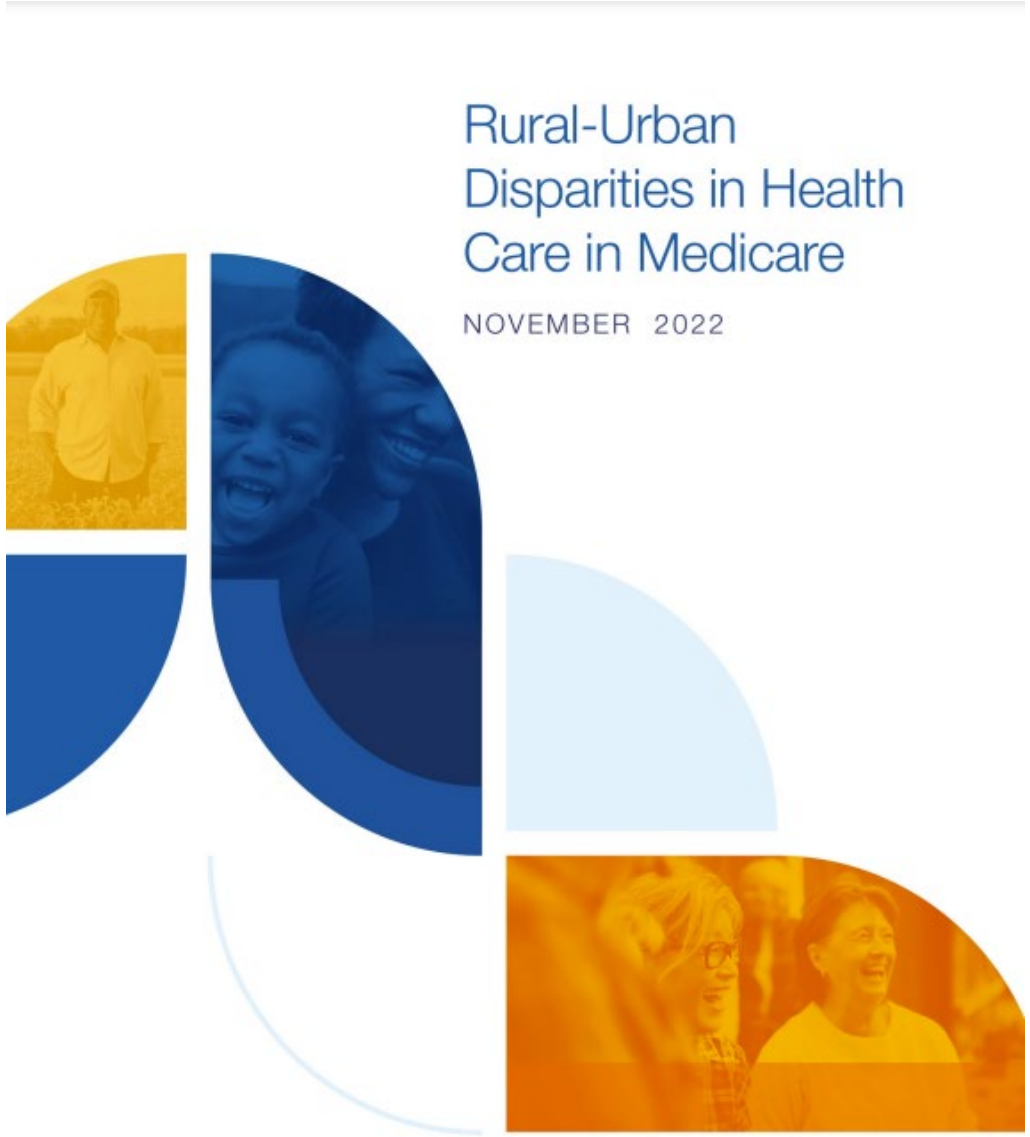
The TDLC Pilot Program offers the following resources at no cost to program participants:

1. Peer learning network;
2. CMS Medicare and Medicaid program data access for 1 year; and
3. Technical support in conducting analyses.

TDLC Program Objectives

- Promoting development of research, analytic methods, and dissemination practices relevant to tribal communities;
- Creating opportunities for participants to network and develop meaningful, sustainable connections with each other;
- Providing timely and tailored technical assistance that enhances participants' capacity to carry out their research; and
- Providing a forum for CMS to engage with TECs along their research lifecycle.

This annual report presents summary information on the quality of health care received by people with Medicare nationwide. The report highlights (1) rural-urban differences in health care experiences and clinical care, (2) how rural-urban differences in quality of care vary by race and ethnicity, and (3) how racial and ethnic differences in quality of care vary between rural and urban areas.



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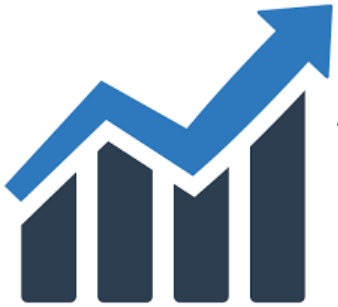
Elements Critical to CMS's Health Equity Data Strategy Success

Working with Partners Across Government and Industry

CMS will continue to collaborate with other federal agencies to receive data, establish standards, and approve program changes to support equity data improvement.



Robust Measurement of Progress

CMS will continuously monitor how CMS data collection, standardization, and use across CMS programs help achieve the following:

- Increase understanding and awareness of disparities and their causes
- Create, test, and implement solutions to advance health equity in CMS programs
- Lead sustainable actions that advance equity in CMS programs

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Coverage to Care

CoverageToCare@cms.hhs.gov

Health Equity Technical Assistance Program

HealthEquityTA@cms.hhs.gov

Rural Health

RuralHealth@cms.hhs.gov

Slides and Recordings from Previous ELS Sessions

https://cmsintranet.share.cms.gov/ER/Pages/CMSEquityLearningSeries.aspx

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Thank You!

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INDIGENIZING DATA: MAPPING A PATH TOWARD HEALTH EQUITY

MYRA PARKER, JD, MPH, PHD

DIRECTOR, SEVEN DIRECTIONS

ASSOCIATE PROFESSOR, DEPT OF PSYCHIATRY AND BEHAVIORAL SCIENCES

UNIVERSITY OF WASHINGTON SCHOOL OF MEDICINE

What do we mean by Indigenizing data collection?

Why is Indigenizing data collection critical for Indigenous Public Health?

Example of how to Indigenize data collection:
Stim a spu'us: What's in Your Heart?

CULTURE MATTERS

DEFINITION OF INDIGENIZING DATA COLLECTION

UTILIZATION OF TRADITIONAL HEALING DIFFERS BY REGION / TRIBE / GENDER

Table 5. Lifetime Help-Seeking Across Comorbidity Groups

Lifetime Use of Services	Southwest Tribe, % (99% CI)			Northern Plains Tribes, % (99% CI)		
	Combined (n = 1446)	Men (n = 617)	Women (n = 829)	Combined (n = 1638)	Men (n = 790)	Women (n-848)
Lifetime Depressive and/or Anxiety Disorder(s) Only						
Mental health professional	34.6 (26.4-43.7)	19.6 (7.8-41.2)	38.6 (29.1-49.0)	40.1 (29.7-51.5)	25.6 (12.2-46.1)	45.4 (32.3-59.1)
Medical professional	29.1 (21.5-38.1)	21.3 (8.5-44.0)	31.2 (22.5-41.3)	37.3 (26.8-49.1)	32.6 (15.4-56.2)	39.0 (26.7-52.8)
Traditional healer	48.9 (40.0-57.9)	40.6 (23.7-60.0)	51.1 (41.0-61.2)	33.7 (23.2-46.0)	39.3 (18.9-64.3)	31.6 (20.2-45.7)
Any help-seeking	66.6 (57.7-74.4)	57.1 (36.2-75.7)	69.1 (59.4-77.4)	63.6 (51.9-73.9)	66.7 (44.1-83.6)	62.5 (48.6-74.6)
Lifetime Substance Use Disorder(s) Only						
Mental health professional	26.1 (19.2-34.3)	25.1 (17.5-34.6)	29.3 (15.8-47.9)	28.6 (22.7-35.2)	25.0 (18.3-33.3)	35.6 (25.1-47.7)
Medical professional	19.0 (13.1-26.7)	20.6 (13.8-29.7)	13.6 (5.0-31.9)	19.4 (14.4-25.6)	17.1 (11.6-24.6)	23.9 (15.0-36.0)
Traditional healer	37.7 (29.7-46.4)*	38.5 (29.4-48.4)†	35.0 (20.2-53.4)	16.9 (12.2-23.0)‡	16.4 (10.9-24.0)§	17.9 (10.1-29.6)
Any help-seeking	55.8 (47.1-64.2)*	55.5 (45.6-65.0)†	56.7 (39.1-72.8)	40.1 (33.6-47.1)‡	36.6 (28.8-45.3)§	47.1 (35.5-58.9)
Lifetime Comorbid Depressive and/or Anxiety and Substance Disorders						
Mental health professional	42.7 (32.3-53.9)	45.7 (31.4-60.8)	39.1 (24.9-55.4)	49.3 (39.7-58.9)	46.4 (31.8-61.7)	51.3 (38.9-63.5)
Medical professional	35.4 (26.0-46.1)	36.7 (24.6-50.7)	33.8 (20.3-50.5)	34.6 (26.2-44.2)	29.5 (17.4-45.5)	38.2 (27.2-50.5)
Traditional healer	61.0 (49.2-71.5)*	59.9 (44.6-73.4)	62.3 (44.0-77.7)	37.4 (28.7-47.1)‡	43.8 (29.3-59.3)	33.0 (22.6-45.4)
Any help-seeking	73.7 (63.3-82.0)	72.0 (58.9-82.2)	75.7 (57.6-87.7)	67.6 (58.0-75.9)	70.3 (54.4-82.5)	65.7 (53.2-76.3)

Abbreviation: CI, confidence interval.
*Significant pairwise comparison with Northern Plains men and women combined.
†Significant pairwise comparison with Northern Plains men.
‡Significant pairwise comparison with Southwest men and women combined.
§Significant pairwise comparison with Southwest men.

Beals, J., Manson, S., Whitesell, N., & Spicer, P. (2005). Prevalence of D5M-IV Disorders and Attendant Help-Seeking in 2 American Indian Reservation Populations. Archives of General Psychiatry, 62(1), 99-108.

CULTURE INFORMS BEHAVIOR, INCLUDING HEALTH PRACTICES

Table 2 Results from the survey by stakeholder group

		Participant group				
		Mothers (n=16)	Teens (n=14)	Young adults (n=22)	Healthcare providers (IHS and tribal) (n=10)	Chi-square (p value)
HPV awareness—how familiar are you with HPV?						
	% Very familiar (n)	12.5 % (2)	7.1 % (1)	4.5 % (1)	30.0 % (3)	26.1 (<0.005)
	% Somewhat familiar (n)	43.8 % (7)	7.1 % (1)	45.5 % (10)	60.0 % (6)	
	% Heard of it, but not familiar (n)	18.8 % (3)	35.7 % (5)	40.9 % (9)	0.0 % (0)	
	% Not at all familiar (n)	25.0 % (4)	50.0 % (7)	4.5 % (1)	0.0 % (0)	
HPV knowledge (true/false questions)						
HPV is spread by sexual contact	% Correctly answered true (n)	43.8 % (7)	42.9 % (6)	54.5 % (12)	70.0 % (7)	2.3 (0.52)
HPV can cause high blood pressure	% Correctly answered false (n)	31.3 % (5)	7.1 % (1)	22.7 % (5)	30.0 % (3)	2.9 (0.41)
HPV can cause cervical cancer	% correctly answered true (n)	68.8 % (11)	28.6 % (4)	86.4 % (19)	70.0 % (7)	13.0 (<0.005)
HPV is a rare infection	% Correctly answered false (n)	37.5 % (6)	0.0 % (0)	40.9 % (9)	40.0 % (4)	8.0 (<0.005)
HPV can cause genital warts	% Correctly answered true (n)	25.0 % (4)	14.3 % (2)	40.9 % (9)	50.0 % (5)	4.6 (0.20)
HPV can cause abnormal Pap smears	% Correctly answered true (n)	50.0 % (8)	7.1 % (1)	45.5 % (10)	70.0 % (7)	10.7 (<0.05)

Schmidt-Grimminger, D., Frerichs, L., Black Bird, A., Workman, E., Dobberpuhl, K., & Watanabe-Galloway, M. (2013). HPV Knowledge, Attitudes, and Beliefs Among Northern Plains American Indian Adolescents, Parents, Young Adults, and Health Professionals. Journal of Cancer Education, 28(2), 357-366.

PRIVILEGING INDIGENOUS KNOWLEDGE SYSTEMS

Relational Epistemologies (Cajete, 2000, 2005)

Centering Place

Working Together for the Good of All

Intergenerational Knowledge Transmission

Indigenous Pedagogies

INDIGENOUS EVALUATION EXAMPLE

Eakins, D., Gaffney, A., Marum, C., Wangmo, T., Parker, M. Magarati, M. (Feb. 2023). Indigenous Evaluation Toolkit for Tribal Public Health Programs: An Actionable Guide for Organizations Serving American Indian/Alaska Native Communities through Opioid Prevention Programming. 7D-Indigenous Evaluation-Toolkit-For-Prevention-Programs.pdf

Figure 2. Indigenous Evaluation Framework
Core Values (LaFrance & Nichols, 2009)

Indigenous Knowledge *Context is Critical*	**People of a Place** *Respect Place-based Programs*	**Centrality of Community and Family** *Connect Evaluation to Community*	**Honoring our Gifts** *Consider the Whole Person when Assessing Merit*	**Sovereignty** Create Ownership and Build Capacity
• Evaluation is woven into the program and Its implementation; it is not an add-on function. • Evaluation is holistic and attends to relationships between the program, its context and community. • Evaluation knowledge honors multiple ways of knowing. • Evaluation recognizes our moral responsibility to reflect on what we are learning and use knowledge to improve our programs and community.	• Honor the place-based nature of many of our programs. • In telling the evaluation story, consider the context, environment, history, community, and contemporary circumstances of the place. • Respect that what works in one setting may not be easily transferred to other situations or places.	• Engage community when planning and implementing an evaluation. • Use participatory practices that engage stakeholders. • Make evaluation processes transparent. • Understand that programs may not focus only on individual achievement, but also on restoring community health and wellbeing.	• Allow for creativity and self-expression. • Use multiple ways to measure accomplishment. • Recognize that people enter programs at different places and with different skills and experience. • Make connections between accomplishment and responsibility.	• Ensure tribal ownership and control of data. • Follow tribal Institutional Review Board processes. • Secure proper permission if future publishing is done. • Build evaluation capacity in the community. • Report in ways meaningful to tribal audiences as well as to funders.

Adapted from Dr. Joan LaFrance, Richard Nichols, and the AIHEC Indigenous Evaluation Framework (2009).

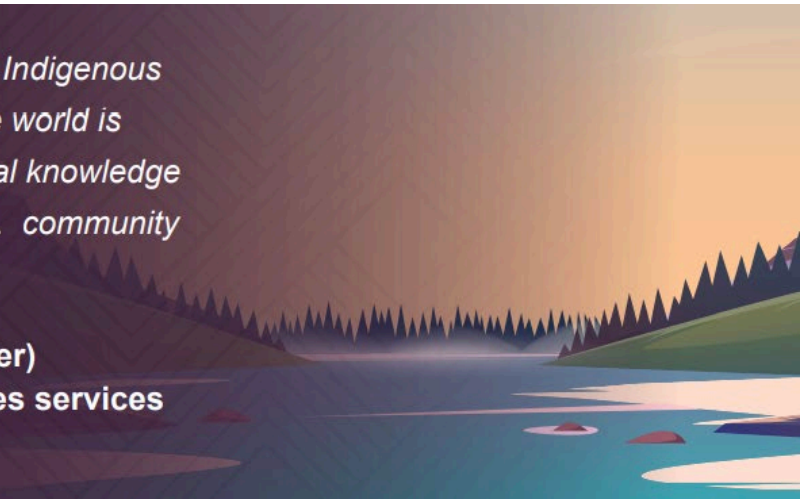
USING METAPHOR AND STORYTELLING

"In Indigenous communities, knowledge is seen in very practical terms. People ask: 'How can it help us or help our community?' Thus, knowledge creation must be framed in practical terms. One way to do this is to use cultural metaphors."

-LaFrance & Nichols (2009)[1]

"[The] focus needs to be on interconnectedness. The Indigenous perspective [is] that everything is interrelated, and the world is holistic. If your air gets sick, you get sick. Engage local knowledge since every tribal community has their own stories . . . community heritage and history are a tool of empowerment."

Dr. David Begay (a traditional healer and Diné Elder) of the University of New Mexico, where he provides services as a cultural consultant



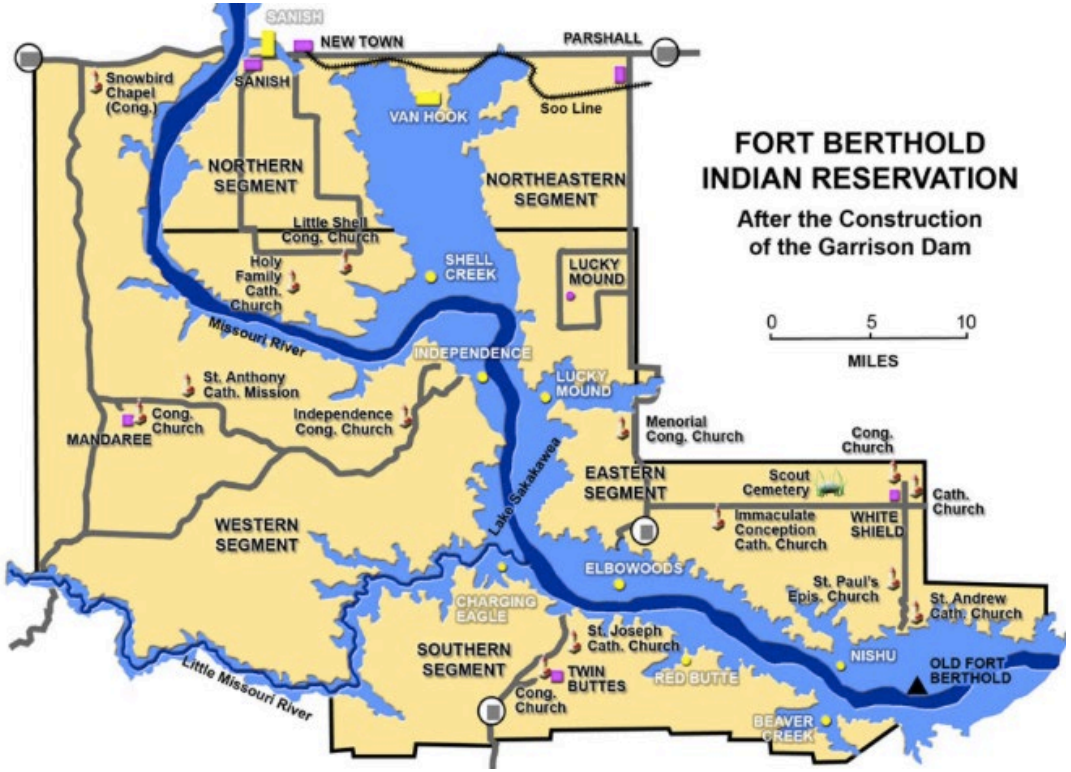
TRADITIONAL CULTURAL PRACTICES BUFFER EFFECTS OF LIFETIME ASSAULTS ON LAKOTA ELDERS

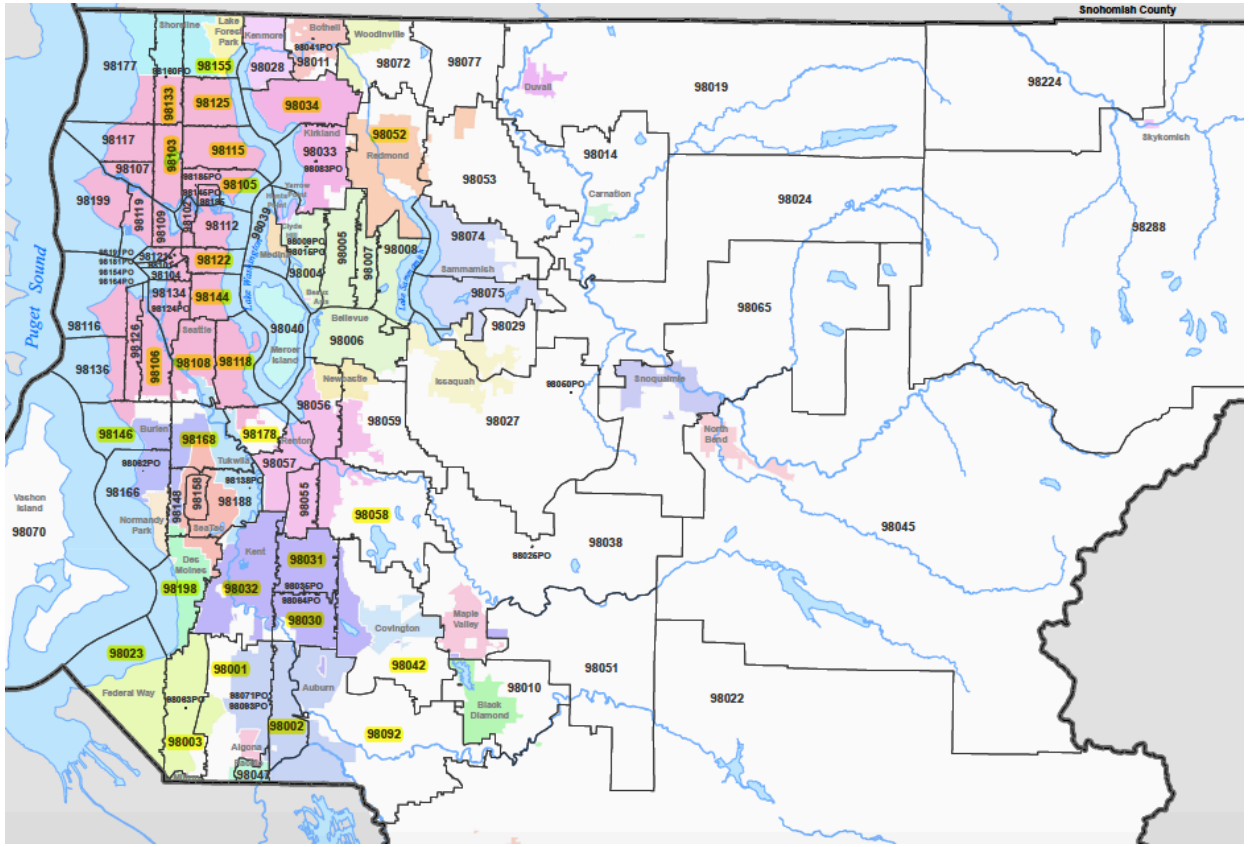
Brave Heart, M.Y. H. (2000). Wakiksuyapi: Carrying the historical trauma of the Lakota. Tulane Studies in Social Welfare, 21-22, 245-266.

CULTURE MATTERS

WHY IS INDIGENIZING DATA COLLECTION CRITICAL FOR INDIGENOUS PUBLIC HEALTH?

DEFINING "PEOPLE OF A PLACE" FOR YOUR COMMUNITY





INCLUDING MODERN CONTEXTS AND STRENGTHS AND RESOURCES WITHIN THE COMMUNITY

HOLISTIC UNDERSTANDINGS OF HEALTH AND WELL-BEING SUPPORT HIGH QUALITY, RELEVANT DATA COLLECTION

CULTURE MATTERS

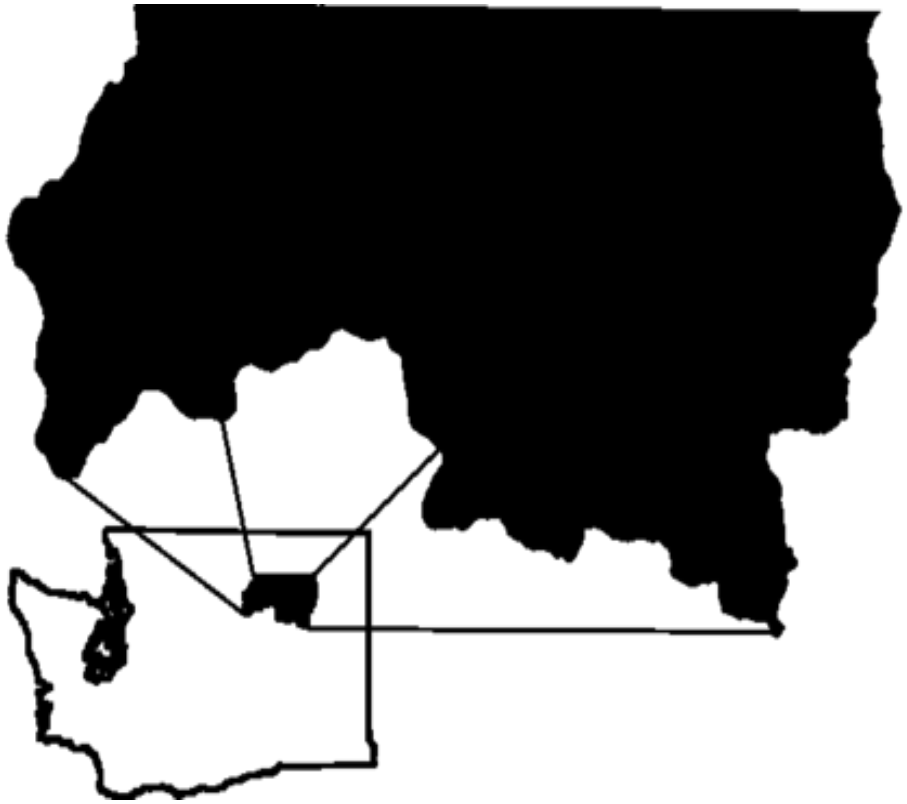
INDIGENIZING DATA COLLECTION IN THE STIM A SPU'US: WHAT'S IN YOUR HEART? PROJECT

STIM A SPU'US: WHAT'S IN YOUR HEART?

Cultural Adaptation of Attachment Vitamins, a trauma-informed, evidence-based parenting intervention

The Confederated Tribe of the Colville Reservation

- Established by Presidential Executive Order (1872)
- 1.4 mil acres located in North Central Washington
  - Originally twice as large as today
- Diversity of natural resources: standing timber, streams, rivers, lakes, minerals, native plants and wildlife
- Governed by the 14 member Colville Business Council



The Confederated Tribe of the Colville Reservation

- Prior to colonization in mid 1850s, ancestors of the 12 aboriginal tribes were nomadic, following the seasons and sources of food
- The aboriginal territories were grouped primarily around waterways: Columbia, Sanpoil, Okanogan, Snake, and Wallowa Rivers

Today: Over 9,365 members of the 12 Tribes

nselxcin	uknaqín	Okanogan	Seeing over the top
	mətxʷu	Methow	Blunt hills around a valley
	snʕáyckst	Lakes	Speckled fish
	sx̌ʷyʔiɬp	Colville	Sharp, pointed trees
	nspilm	Nespelem	Prairie
	sənpʕʷilx	San Poil	Grey mist as far as one can see
nxaʔamxčín	šk̓wáxčənəxʷ	Moses-Columbia	People living on the bank
	šnṕəšqʷáẃšəxʷ	Wenatchi	People in the between
	šnt̓iyátkʷəxʷ	Entiat	Grass in the water
	ščəl̓ámxəxʷ	Chelan	Deep water
nimipu	wal̓wáma	Nez Perce	Joseph Band, Wallowa People
	palúšpam	Palouse	Palus People

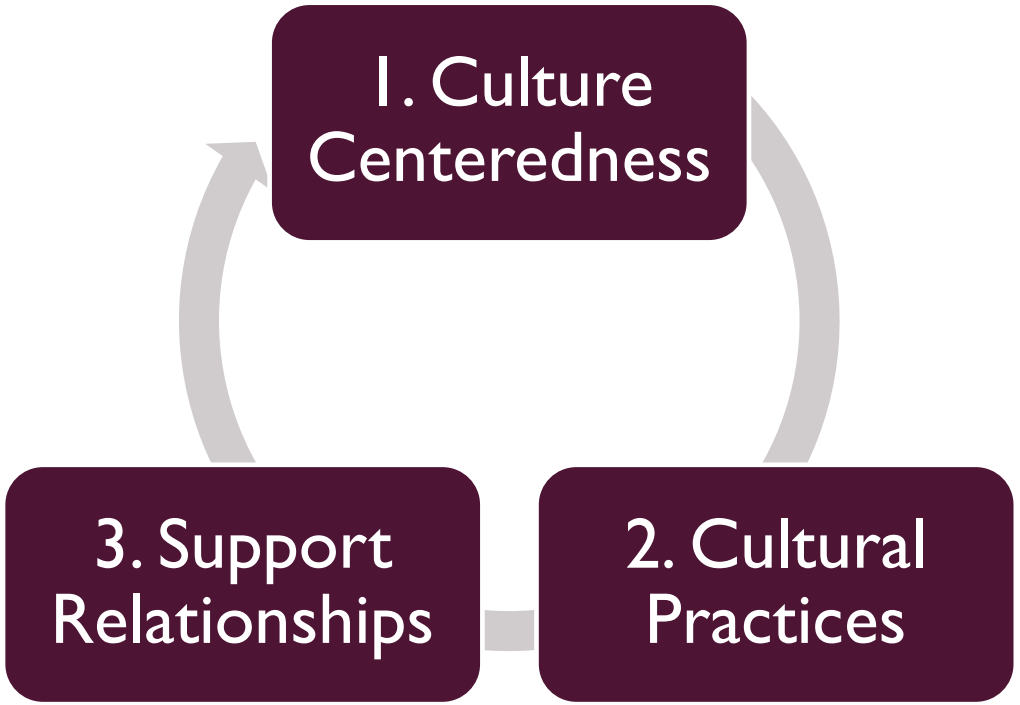
Image of dancers at powwow owned by Alvina Marris

CULTURALLY-ADAPTED PARENTING PROGRAM

- Group program for caregivers of young children
- 6 weekly meetings facilitated by two trained community members
- Core elements of every meeting:
  - Psychoeducational curriculum
  - Reflective discussion among caregivers
  - Sharing Moments of Connection
  - Storytime

Image of infant owned by Alvina Marris

PRIVILEGING COMMUNITY STRENGTHS AS A SOURCE OF RESILIENCE



1. Identify and integrate tribal traditions, knowledge systems, and norms
2. Rebuild and revitalize "praxis" within and with community
3. Own roles and power in strengthening family connectedness

Results: Intergenerational strengths

My mom talks about that nurturing she got from her grandma, and every time she talks about it I can see in her eyes, I can feel that sweet gentless of my great grandma and it makes me feel like a little tiny baby [protected and loved] - Language Expert

I remember more my great-grandmother and grandparents being there for me, as being these caring, nurturing individuals… And then when my sister… when there was a deep illness, I saw a lot of that care really double upon the child - Elder

Results: Traditional lifeways

When they [grandparents] *take you out in the mountains and they want you to follow them and they wanna teach you why this is growing that way and why you pick this on that season and stuff like that. And culturally speaking, that's a part of parenting that, grandparents and mothers and fathers… we used to come to the country and up in the mountains for weeks at a time and pick huckleberries and things because that's what you're supposed to do. That's just what we knew to do.* - Elder

I think keeping my kids in tune with a lot of the culture and values that I was raised with by my parent, my mom, and my grandparents, is kinda what I try to instill in my children, because it's part of who we are as a people. It's important to keep those cultures alive by teaching my kids those. - Caregiver

Results: Desire to gain traditional knowledge

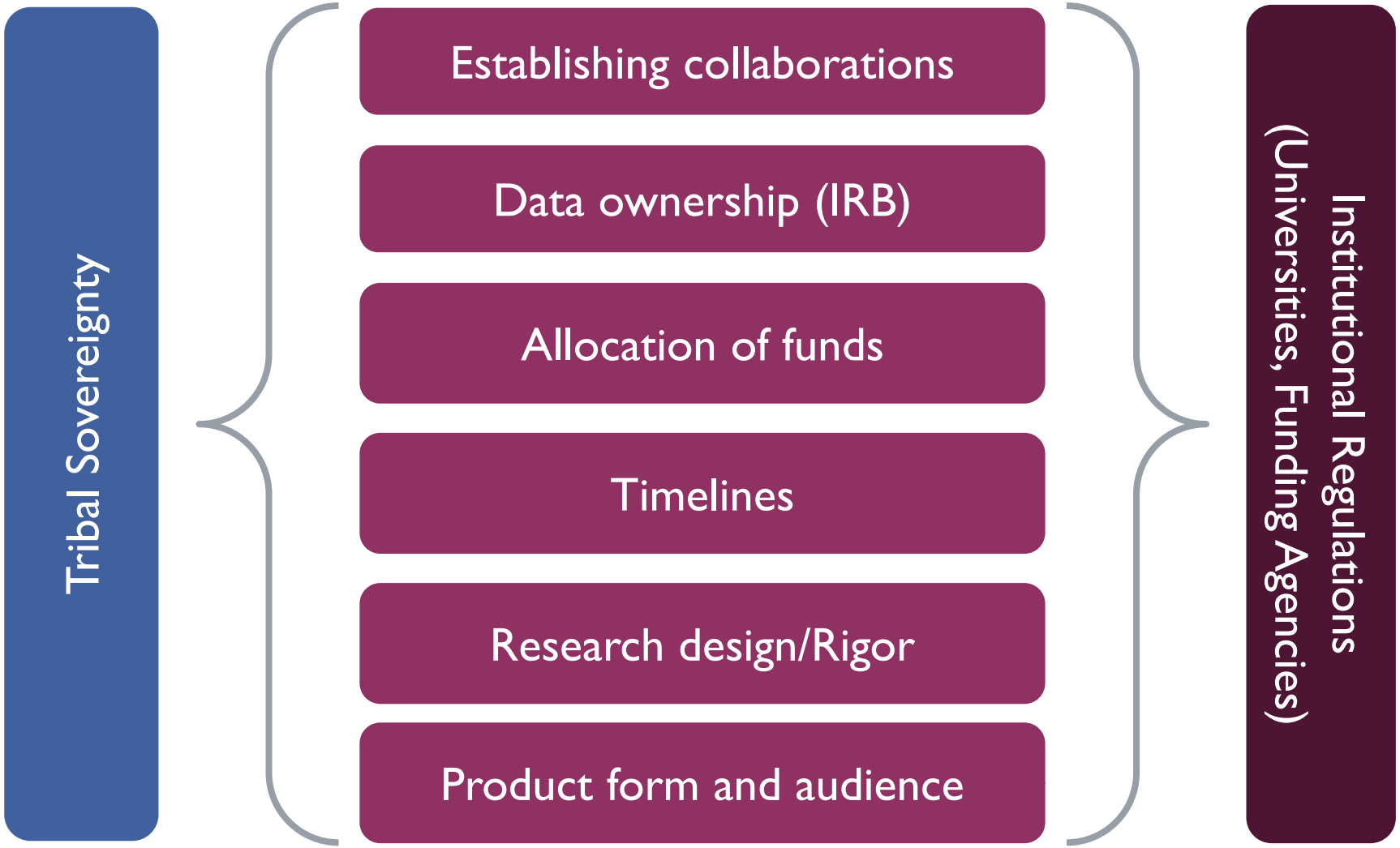
So we weren't raised culturally, like, traditionally, but I do have some aspects of that of being around my grandparents up here. So I know about what to do during a funeral and stuff like that, but not, not fully cultural. And I feel now that I'm an adult and have children of my own, I wish I did know that because culture is a lot for our members and we just don't have the resources. Like, we do and we don't. - Caregiver

If I could do it, I would put my whole heart into our culture 'cause it does make it feel like I'm missing out to not know the culture and I wasn't raised and I cannot speak any type of Salish anything, and it sucks because I can't teach my children that. - Caregiver

Guiding values and goals

- Caregivers in community with one another
  - Group format
  - Facilitation by trained community members
- Multigenerational healing
  - Sensitivity to differences in awareness of historical trauma
  - Sensitivity to differences in knowledge of traditional practices
- Long-term sustainability
  - Where the program “lives” and what that means

Tensions in culturally grounded tribal prevention



CLOSING

- Indigenizing data collection
  - Strengthens critical relationships.
  - Heightens our understanding of why participants engage with programming or make other health decisions.
  - Supports ongoing identity development, across generations.
  - Centers AIAN resiliency and healing.

RESOURCES

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RESOURCES

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RESOURCES

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Thank you!

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We are More than Numbers

Impacts of different counts and definitions of Alaska Native and American Indian people

Prepared for
Tribal Health Equity Data Symposium
September 25, 2023

ALASKA NATIVE
TRIBAL HEALTH
CONSORTIUM

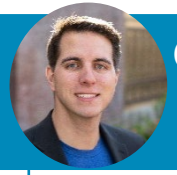
Agenda

1. The legal context and background of “we are more than numbers”
2. Which definitions are widely used for AN/AI population?
3. Alaska Tribal Health System Operational Definition and the foundation of Population Health

ALASKA NATIVE TRIBAL HEALTH CONSORTIUM

1. The legal context & background of “we are more than numbers”

Corporations and Villages in Alaska

	 **Rachael DeMarce** **American Indian**	 **Geoffrey Bacon** **Alaska Native**
Tribe Of the 574 federally recognized Tribal Nations, 229 are located in Alaska	• Little Shell Tribe of Chippewa Indians, Tribal Member • Blackfeet Nation, Descendant	Native Village of Tanana, Tribal Member
Village Corporation	Not Applicable	Tozitna Limited, Descendant of Shareholder
Regional Corporation		Doyon Limited, Shareholder

Governing bodies of Alaska Native communities vary from tribe or village "traditional councils," to "Native councils," "village councils," "tribal councils, or "IRA councils."

In some instances, the term "village" is used instead of "tribe," as tribal nations in Alaska were often recognized by the term "village" under the Alaska Native Claims Settlement Act (ANCSA) of 1971.

Hirschfield, M. (1991). The Alaska Native Claims Settlement Act: tribal sovereignty and the corporate form. Yale LJ, 101, 1331.

ALASKA NATIVE TRIBAL HEALTH CONSORTIUM

Legal Authority for Tribal Health & Federal Trust Responsibility

1789-1844

Indian Affairs (Indian Health) under jurisdiction of the Department of War

1832-1871

Federal government made approx. 210 treaties with Indian Tribes; about ¼ include health services in exchange for land

1921

25 U.S.C. § 13 (Snyder Act of 1921) ("The BIA, . . . Shall direct supervise, and expend such moneys as Congress may . . . Appropriate, for the benefit, care, and assistance of the Indians throughout the United States for the following purposes: ***For relief of distress and **conservation of health**.")

1954

42 U.S.C. § § 201 et seq. Alaska Native Health Service transferred to Division of Indian Health

1975

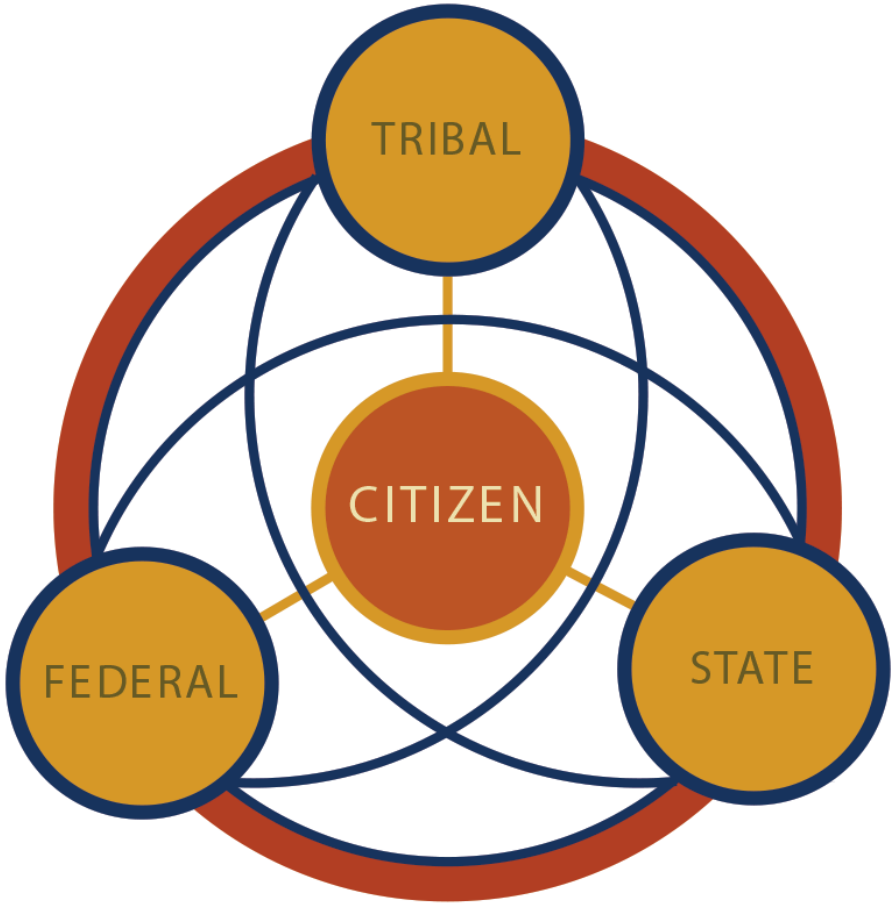
25 U.S.C. § § 5301 et seq. (Indian Self-Determination and Education Assistance Act) **Authorized Indian Tribes to operate IHS programs and later compact**

1976

25 U.S.C. § § 1601 et seq. (Indian Health Care Improvement Act and Declaration) **explaining trust responsibility and legal obligations** to Indians

ALASKA NATIVE TRIBAL HEALTH CONSORTIUM

Alaska Native and American Indian (AN/AI) people have a unique legal and political relationship with the United States



"AN/AI peoples and governments have inherent rights and a political relationship with the U.S. government that **does not derive from race or ethnicity**.

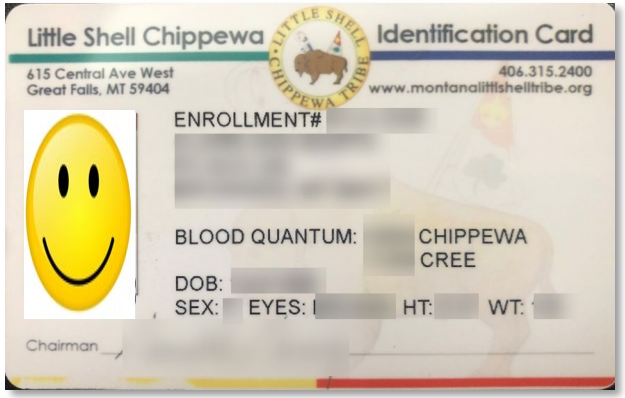
Tribal citizens are citizens of three sovereigns: their tribal nations, the United States, and the state in which they reside. They are also individuals in an international context with the rights afforded to any other individual."

Source: Indian Country 101, National Congress of American Indians
https://www.ncai.org/tribalnations/introduction/Indian_Country_101_Updated_February_2019.pdf

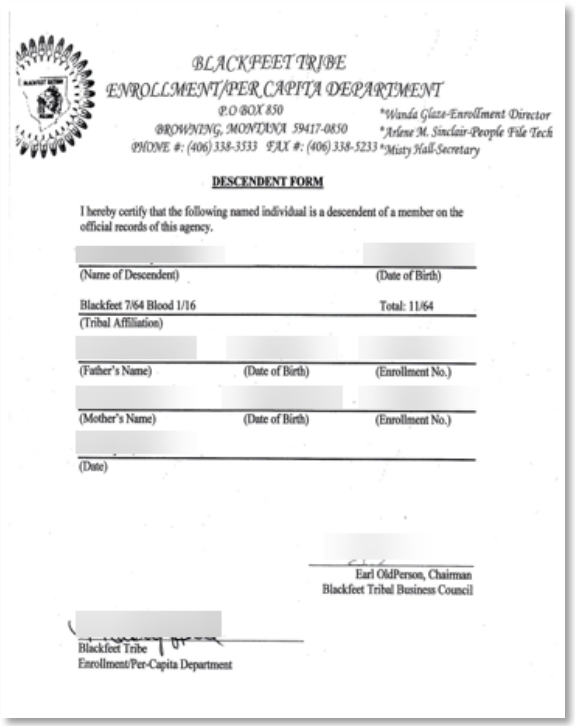
ALASKA NATIVE TRIBAL HEALTH CONSORTIUM

Tribal Affiliation Documentation Examples

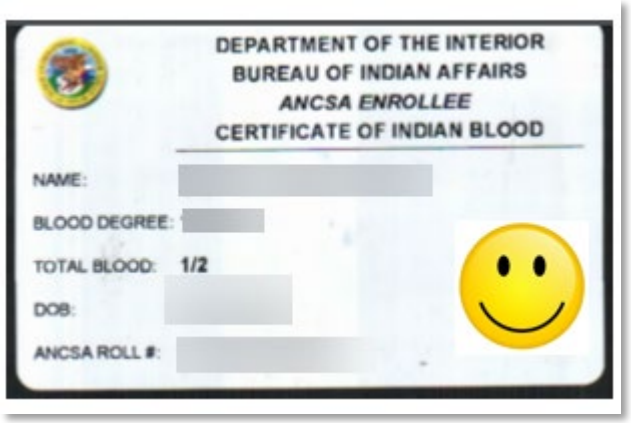
Tribal Nation ID Card



Tribal Letter



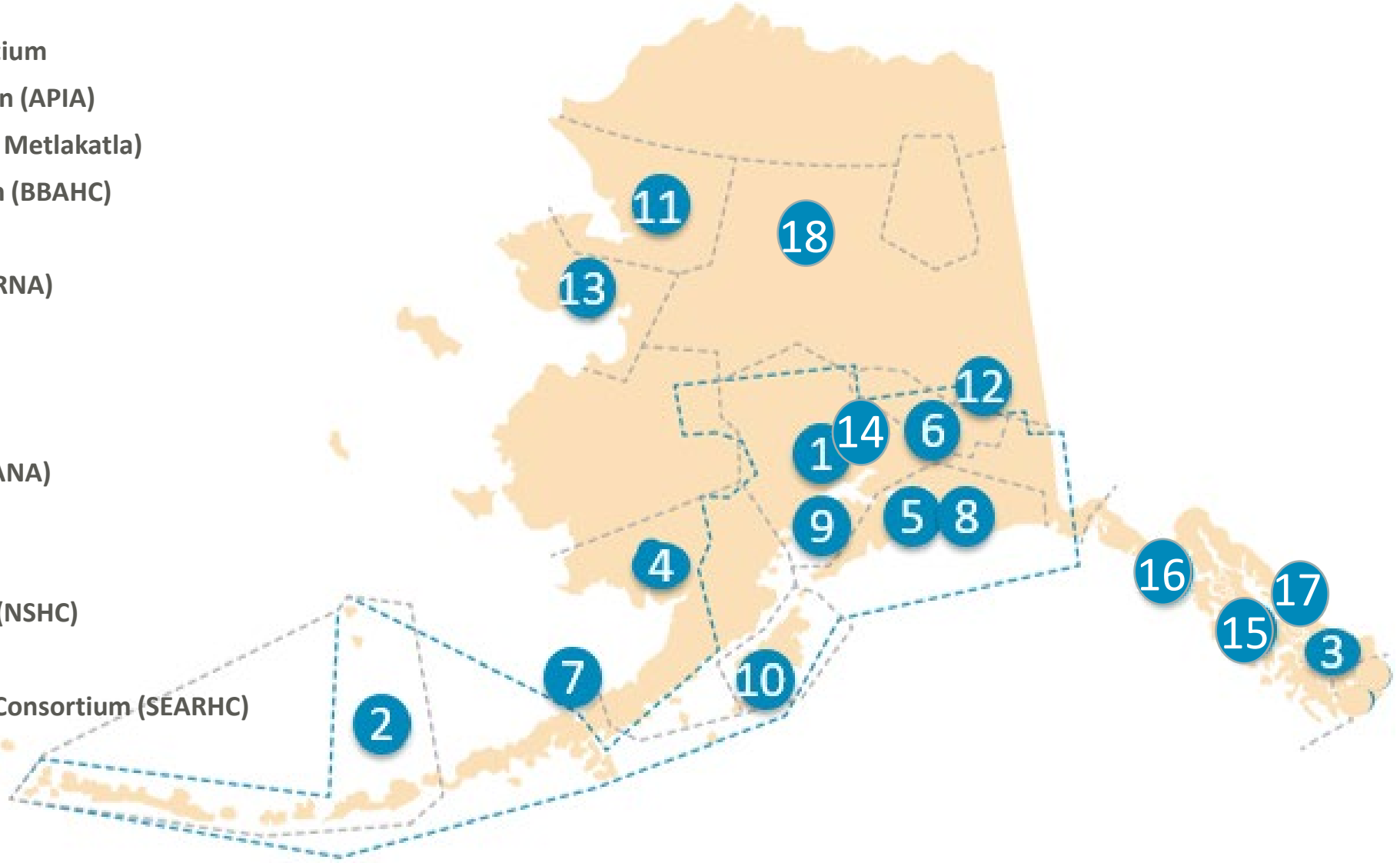
Bureau of Indian Affairs Form or Card



ANSCA Documentation

Shared Tribal Analytics & Reporting
ANTHC Data & Analytics Provides Statewide Analytics Support

1. Alaska Native Tribal Health Consortium
2. Aleutian Pribilof Islands Corporation (APIA)
3. Annette Island Service Unit (AISU – Metlakatla)
4. Bristol Bay Area Health Corporation (BBAHC)
5. Chugachmiut
6. Copper River Native Association (CRNA)
7. Eastern Aleutian Tribes (EAT)
8. Ilanka Community Health Center
9. Kenaitze Indian Tribe
10. Kodiak Area Native Association (KANA)
11. Maniilaq Association
12. Mount Sanford Tribal Consortium
13. Norton Sound Health Corporation (NSHC)
14. Southcentral Foundation (SCF)
15. Southeast Alaska Regional Health Consortium (SEARHC)
16. Yakutat Community Health Center
17. Ketchikan Indian Community
18. Tanana Chiefs Conference



Shared Analytics Enterprise Data Warehouse (EDW)

Source Systems

Databases from transactional workflow systems act as the primary sources for the data warehouse. Thee systems are designed to support transactions, not analytics!

Example Data Sources:

- Cerner EHR
- Infor
- Kronos
- Lab
- VacTrAK

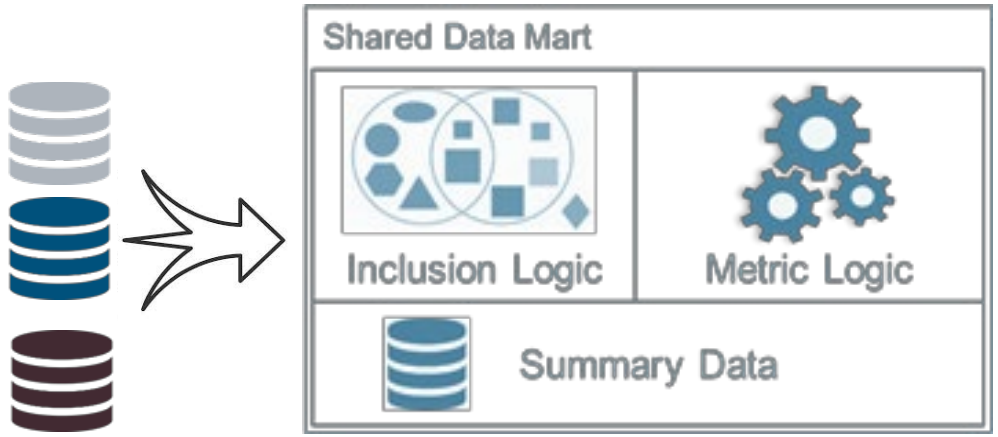
Data Operating System

Source Marts

Minimally transformed tables from source systems.

Subject Area Marts (SAM)

Data is selected and frequently blended from multiple data sources. Data transformations and logic are applied to create meaning and standardization at the SAM/pre-deployment level.



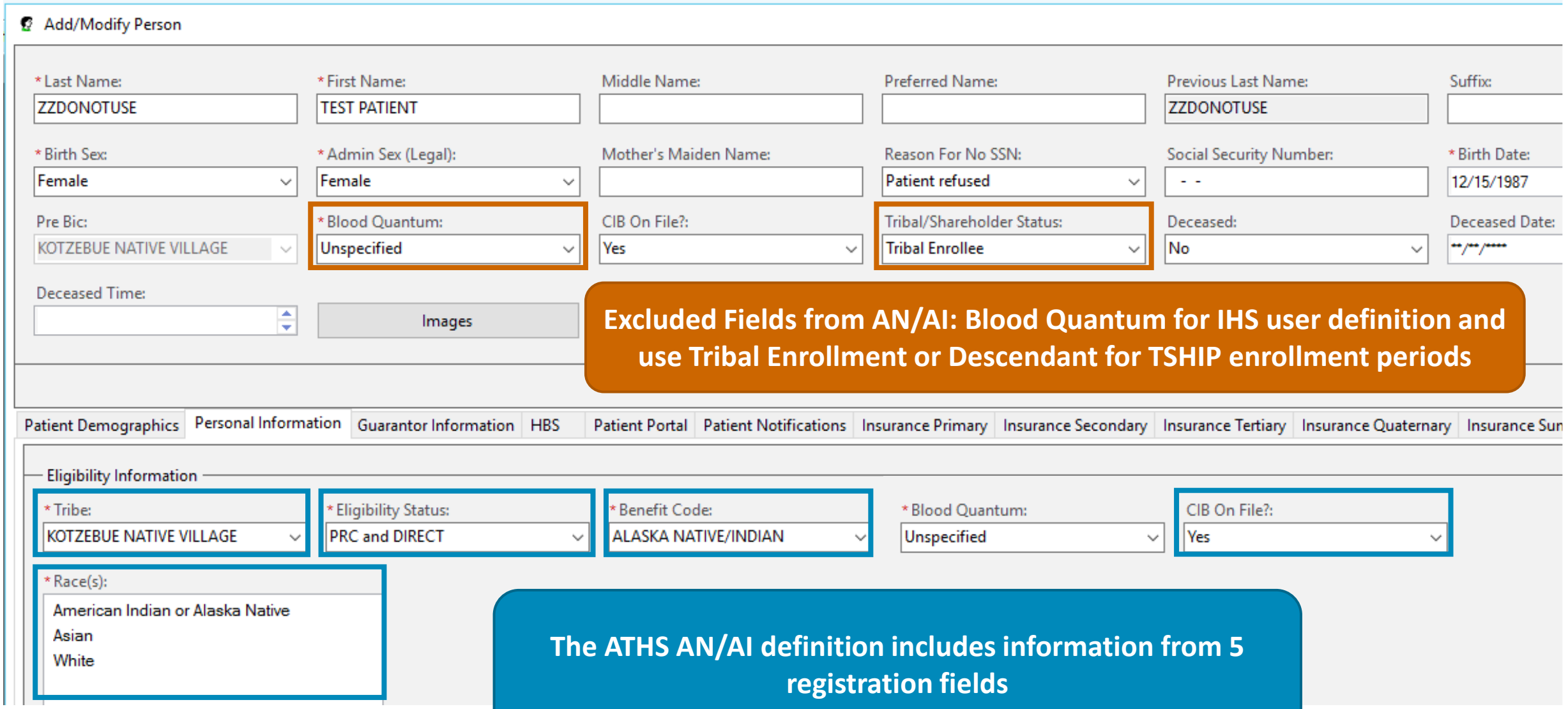
Distribution and Deployment of Products

Content delivered to end-users as reports, dashboards, analytics applications, etc.

Dashboards and Explorers

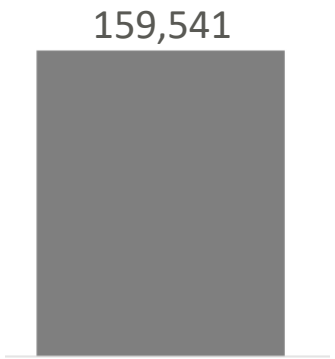
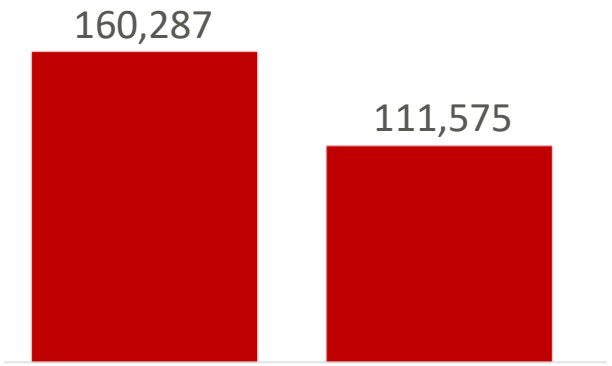
Population Analyzer

Registration View of Patient Demographic Fields in Shared EHR



2. Which definitions are widely used for AN/AI population?

Definitions of AI/AN population vary by authority for Alaska

POPULATION ESTIMATE:				
ORGANIZATION:	**IHS**	**US Census**	**HRSA UDS**	**ANTHC & ATHS**
REPRESENTS:	Active Patients in Alaska IHS Service Area	AI/AN Residents Responding to the 2020 Decennial Census	Participating Health Center Programs in Alaska (27 Program Awardees including 10 THOs)	Patients within Shared EHR (Roughly 75% of AN/AI Patients in AK)

Methods are based on current understanding and publicly available information.

Review: Methods for Defining Alaska Native and American Indian People

ORGANIZATION	IHS	US Census	HRSA (UDS)	ANTHC & ATHS
TRIBE	✓	✓		✓
ELIGIBILITY STATUS				✓
BENEFIT CODE	✓			✓
BLOOD QUANTUM	✓			
RACE (ALONE)		✓	✓	✓
RACE (MULTIPLE SELECTIONS REMAIN)		✓		✓
RACE (MULTIPLE CONDENSE TO OTHER OR MULTIPLE FIELD)			✓	
TIME PERIOD	3 year inclusion (Oct 1 – Sep 30)	Decennial: Every 10 years	1 year inclusion (Jan 1 – Dec 31)	2011 or when THO joined shared EHR

IHS: Definition using Tribe or Tribe and Benefit Code / Blood Quantum

ORGANIZATION	IHS
POPULATION IN ALASKA SERVICE AREA	159,541
TRIBE	✓
ELIGIBILITY STATUS	
BENEFIT CODE	✓
BLOOD QUANTUM	✓
RACE (ALONE)	
RACE (MULTIPLE SELECTIONS REMAIN)	
RACE (MULTIPLE CONDENSE TO OTHER OR MULTIPLE FIELD)	
TIME PERIOD	3 year inclusion (Oct 1 – Sep 30)

Indian Status

Indian Status determination is made based on current values for each Registration ID (REG_ID). A patient will be considered an Indian (IndianStatusFlag = 'Y') if that patient meets one of the following criteria:

- Member of a federally recognized Tribe (Tribe Code[2] = '000' – '997' and Indian Flag[3] = 'Indian')
- Tribe Code = '998' or '999' and Beneficiary Code = '01'
- Tribe Code = '998' or '999' and Indian Blood Quantum[4] = '1' or '2' or '3' or '4'

In all other cases, the patient will be considered as non-Indian.

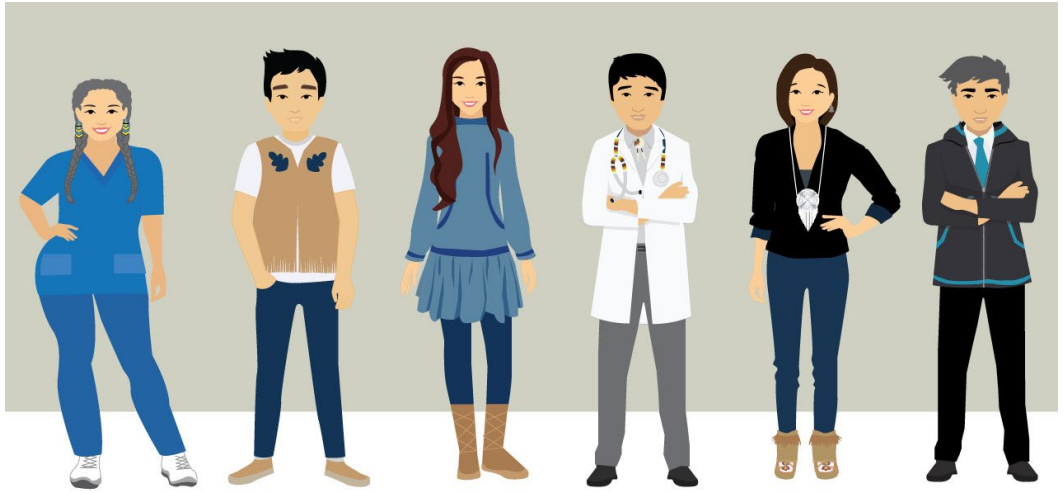
The Indian Status of the non-duplicate registration record determines how the person is represented on the User Population report.

Source: National Patient Information Reporting System, National Data Warehouse, Basic Business Rules https://www.ihs.gov/sites/npirs/themes/responsive2017/display_objects/documents/WUPS/NPIRS_Basic_Business_Rules.pdf

IHS: Financial Uses of NDW User Population Counts

Directly used for:

- Indian Health Care Improvement Fund (IHCIF)
- Health Facilities Construction Programs
- Maintenance & Improvement Programs (M&I)
- Opioid settlements (*Alaska is utilizing Census data*)



**Note: IHS does not disclose specific funding calculations*

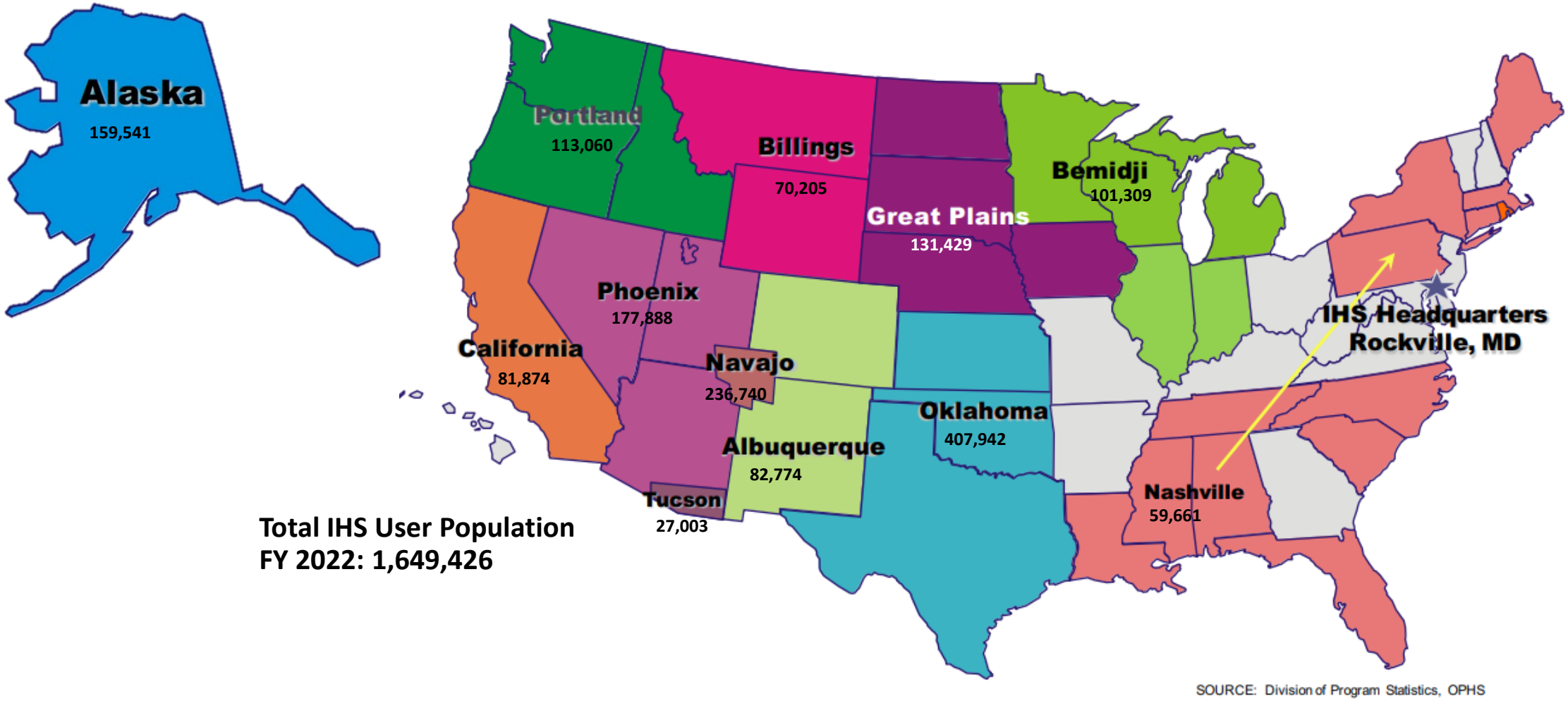
Component of funding calculations* for:

- Tribal Shares Formula

  Tribal Health Organizations (THOs) may elect to assume responsibility for Programs, Services, Functions, and Activities (PSFAs) formerly administered by the Indian Health Service (IHS) and negotiated during compact funding

- Purchased and Referred Care (PRC) Formula
- Special Diabetes Program for Indians (SDPI)
- Methamphetamine and Suicide Prevention Initiative (MSPI) and the Domestic Violence Prevention Initiative (DVPI)

IHS: Nationwide counts of Active Patients utilizing Tribal Health Systems

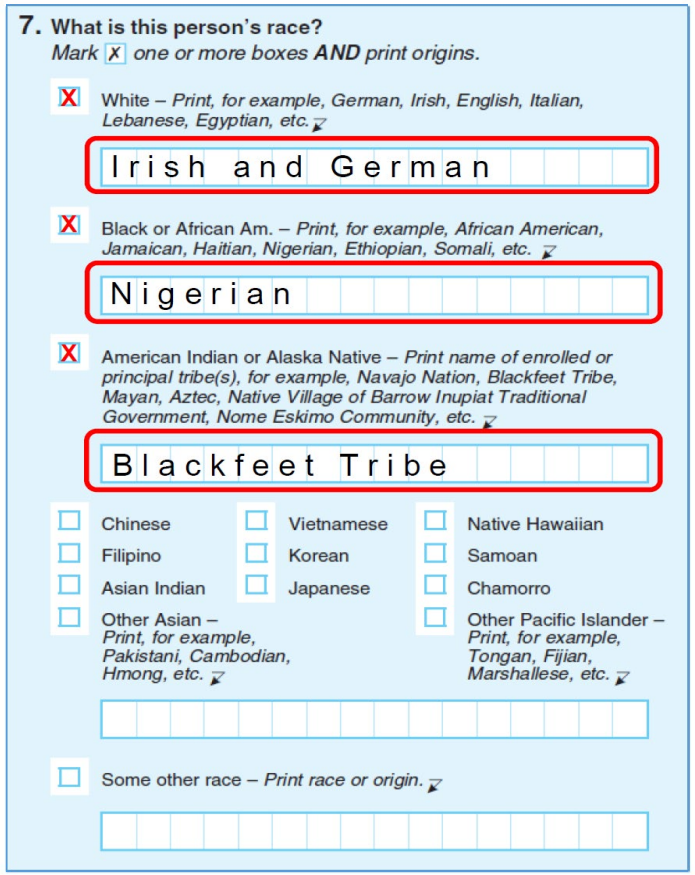


Adapted from Alaska Native Health Service (May 2016) with FY2022 Indian User Population Estimates shared with permission from IHS. User counts are based on registration and encounter data received in the IHS National Patient Information Reporting System (NPIRS) repositories. Portions of the Navajo service region map incorrectly extends over the Ute and Hopi Tribes.

US Census Bureau: Data collection and enumeration

ORGANIZATION	US Census
AN/AI IN COMBINATION IN ALASKA (2020)	160,287
TRIBE	✓
ELIGIBILITY STATUS	
BENEFIT CODE	
BLOOD QUANTUM	
RACE (ALONE)	✓
RACE (MULTIPLE SELECTIONS REMAIN)	✓
RACE (MULTIPLE CONDENSE TO OTHER OR MULTIPLE FIELD)	
TIME PERIOD	Decennial (Every 10 years)

Separate Race Question



7. What is this person's race?
*Mark [X] one or more boxes **AND** print origins.*

[X] White – *Print, for example, German, Irish, English, Italian, Lebanese, Egyptian, etc.*
Irish and German

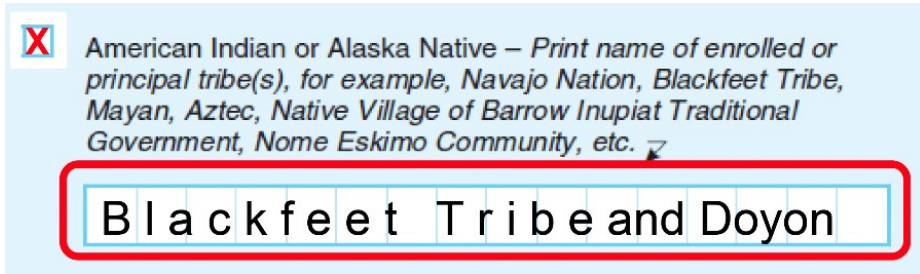
[X] Black or African Am. – *Print, for example, African American, Jamaican, Haitian, Nigerian, Ethiopian, Somali, etc.*
Nigerian

[X] American Indian or Alaska Native – *Print name of enrolled or principal tribe(s), for example, Navajo Nation, Blackfeet Tribe, Mayan, Aztec, Native Village of Barrow Inupiat Traditional Government, Nome Eskimo Community, etc.*
Blackfeet Tribe

[ ] Chinese [ ] Vietnamese [ ] Native Hawaiian
[ ] Filipino [ ] Korean [ ] Samoan
[ ] Asian Indian [ ] Japanese [ ] Chamorro
[ ] Other Asian – *Print, for example, Pakistani, Cambodian, Hmong, etc.* [ ] Other Pacific Islander – *Print, for example, Tongan, Fijian, Marshallese, etc.*

[ ] Some other race – *Print race or origin.*

2020 Census Data Collection Operation Captured Up to 200 Characters and Coded Up to Six Groups



[X] American Indian or Alaska Native – *Print name of enrolled or principal tribe(s), for example, Navajo Nation, Blackfeet Tribe, Mayan, Aztec, Native Village of Barrow Inupiat Traditional Government, Nome Eskimo Community, etc.*
Blackfeet Tribe and Doyon

Source: Population Division, US Census Bureau, Collecting and Tabulating Ethnicity and Race Responses in the 2020 Census, https://www2.census.gov/about/training-workshops/2020/2020-02-19-pop-presentation.pdf

Outreach by Alaska Federation of Natives

- Each Alaska Native person counted in the Decennial Census helps contribute almost **$3,500 annually** for tribal programs such as Head Start, SNAP, TANF, and WIC.
- For a Native family of four this means about **$14,000 annually**.

Source: United States Census Bureau estimates of the per-person allocation of federal funding, https://firstalaskans.org/census-information-center/overview/

2020 U.S. CENSUS OUTREACH

The 2020 Census is more than a population count. It's an opportunity to shape the future of the Alaska Native community.

If you're Alaska Native, you can help tribal communities and programs across the state get their fair share of federal funding by following three easy steps. YOU MATTER!

STEP 1: FILL OUT THE FORM

- Alaska receives almost $3.5 billion dollars in federal funding annually based on U.S. Census data.
- If you're Alaska Native, but you don't fill out the form, your community could lose almost $3,500 annually for tribal programs such as Head Start, SNAP, TANF, and WIC.
- If a Native family of four isn't counted, your community could lose about $14,000 annually.
- 10 questions, 10 minutes, 10 years of impacts.

STEP 2: LIST YOURSELF AS 'PERSON 1'

- If you're Alaska Native, and you live in a mixed Native and non-Native (White) household—whether you're a spouse or significant other—please list the Native person as 'Person 1' for question 5.
- If 'Person 1' says he or she is 'American Indian or Alaska Native,' then the entire household is counted as one with a Native head of household.
- 'Person 1' doesn't have to be male or pay more than half of the household expenses.

STEP 3: WRITE IN YOUR TRIBE

- If you're Alaska Native, please list the name of your federally recognized tribe—as opposed to your regional or village corporation—for question 9.
- If you can't remember the name for your tribe, you can write in the name of your village. You can even write in more than one tribe (or village) if you associate with more than one.
- All of the federally recognized tribes in Alaska are listed at https://www.nativefederation.org/2020/02/aktribes/

#AlaskaNativesCount
#ThreeSteps

For more information, please contact
Nicole Borromeo at 907-263-1310 or
nborromeo@nativefederation.org

US Census Bureau: Dissemination of demographic data

111,575	**Alone**
111,575	**American Indian and Alaska Native alone**
48,712	**In Combination**
42,612	**Population of two races**
38,129	White; American Indian and Alaska Native
2,039	Black or African American; American Indian and Alaska Native
1,215	American Indian and Alaska Native; Asian
622	American Indian and Alaska Native; Some Other Race
607	American Indian and Alaska Native; Native Hawaiian and Other Pacific Islander
5,290	**Population of three races**
704	**Population of four races**
93	**Population of five races**
13	**Population of six races**
160,287	**Total AN/AI Responses in 2020 Census Redistricting File for Alaska**

Source: Decennial Census, US Census Bureau, DEC Redistricting Data (PL 94-171) Total Population for American Indian and Alaska Native, https://data.census.gov/table?q=American+Indian+and+Alaska+Native&tid=DECENNIALPL2020.P1

Ambiguity in Census data collection and proposed OMB updates on inclusion for “American Indian or Alaska Native”

Definition used during 2020 Decennial Census:

American Indian or Alaska Native. A person having origins in any of the original peoples of North and South America (including Central America) and who maintains tribal affiliation or community attachment. This category includes people who indicate their race as “American Indian or Alaska Native,” or report responses such as Navajo Nation, Blackfeet Tribe, Mayan, Aztec, Native Village of Barrow Inupiat Traditional Government, or Nome Eskimo Community.

Source: US Census Bureau, 2020 Census State Redistricting Data (Public Law 94-171) Summary File, https://www2.census.gov/programs-surveys/decennial/2020/technical-documentation/complete-tech-docs/summary-file/2020Census_PL94_171Redistricting_StatesTechDoc_English.pdf

Initial Proposals For Updating OMB’s Race and Ethnicity Statistical Standards:

ANTHC proposed the removal of Central and South America from the description of “American Indian or Alaska Native.” AN/AI status is a legal and political description that is based on the federal trust responsibility.

ALASKA NATIVE TRIBAL HEALTH CONSORTIUM

Example: New Zealand 2023 Census

Paper form

8 Which ethnic group do you belong to?
Mark the space or spaces which apply to you.

- New Zealand European
- Māori
- Samoan
- Cook Islands Maori
- Tongan
- Niuean
- Chinese
- Indian
- other, eg DUTCH, JAPANESE, TOKELAUAN. Please state:

Paper form

12 Are you descended from Māori (that is, did you have a Māori birth parent, grandparent or great-grandparent, etc)?

- yes → go to **13**
- don't know → go to **13**
- no → go to **14**

13 Do you know the name(s) of your iwi (tribe or tribes)?

See the Guide Notes for a list of iwi.

- yes
- no → go to **14**

↳ give the name(s) and region(s) / rohe of your iwi:

iwi:

region (rohe):

iwi:

region (rohe):

iwi:

region (rohe):

iwi:

region (rohe):

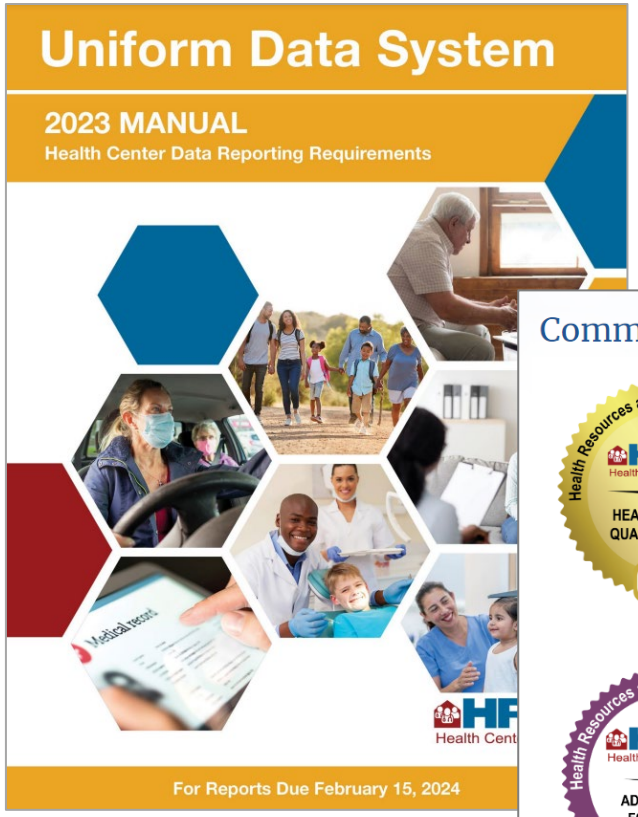
iwi:

region (rohe):

2023 Census | Aotearoa New Zealand. "What Questions Are in the 2023 Census." Accessed September 18, 2023. https://www.census.govt.nz/what-questions-are-in-the-2023-census/.

HRSA: AN/AI reporting for the Uniform Data System (UDS)

ORGANIZATION	HRSA Health Center Program HRSA (UDS)
PATIENTS REPORTED IN ALASKA PROGRAMS	39,848
TRIBE	
ELIGIBILITY STATUS	
BENEFIT CODE	
BLOOD QUANTUM	
RACE (ALONE)	✓
RACE (MULTIPLE SELECTIONS REMAIN)	
RACE (MULTIPLE CONDENSE TO OTHER OR MULTIPLE FIELD)	✓
TIME PERIOD	1 year inclusion (Jan 1 – Dec 31)



> "Health centers receive Health Center Program federal grant funding to improve the health of underserved populations."

**Note that percentages represent the number of health center awardees that met the criteria for each CHQR badge from a denominator of health centers that reported UDS data.*

Source: Uniform Data System, Health Resources & Security Administration, Alaska Health Center Program Uniform Data System (UDS) Data Website, https://data.hrsa.gov/tools/data-reporting/program-data/state/AK

HRSA: Multiracial patients reported as “More than One Race”

Table 3B: Patients by Race and Hispanic, Latino/a, or Spanish Ethnicity		UDS Calendar Year 2022	
Line	**Patients by Race**	**Patients in AK**	**% of Total**
1a	Asian Indian		
1b	Chinese		
1c	Filipino		
1d	Japanese		
1e	Korean		
1f	Vietnamese		
1g	Other Asian		
1	Total Asian (Sum Lines 1a+1b+1c+1d+1e+1f+1g)		
2a	Native Hawaiian		
2b	Other Pacific Islander		
2c	Guamanian or Chamorro		
2d	Samoan		
2	Total Native Hawaiian/Other Pacific Islander (Sum Lines 2a+2b+2c+2d)		
3	Black/African American		
4	**American Indian/Alaska Native**	**39,848**	**41.45%**
5	White		
6	**More than one race**	**2,561**	**2.66%**
7	Unreported/Chose not to disclose race		
8	**Total Patients** (Sum of Lines 1 + 2 + 3 to 7)		

Source: Uniform Data System, HRSA, Alaska Health Center Program Uniform Data System (UDS) Data, https://data.hrsa.gov/tools/data-reporting/program-data/state/AK
Source: Uniform Data System, HRSA, 2023 UDS Manual, https://bphc.hrsa.gov/sites/default/files/bphc/data-reporting/2023-uds-manual.pdf

3. Alaska Tribal Health System Operational Definition and the foundation of Population Health

CRC Example CMS130AK Age 40-75
Hypothetical Example Population of 35,000

20,000
Patients Screened for CRC

30,000
Under count AN/AI 5,000

66%

20,000
Patients Screened for CRC

40,000
Over count AN/AI 5,000

50%

Hypothetical rates are examples and do not represent the Alaska Tribal Health System.

Alaska Tribal Health System Operational Definition

ORGANIZATION	ALASKA NATIVE TRIBAL HEALTH CONSORTIUM ANTHC & ANMC
PATIENTS REPORTING IN ALASKA PROGRAMS	205,000
TRIBE	✓
ELIGIBILITY STATUS	✓
BENEFIT CODE	✓
BLOOD QUANTUM	
RACE (ALONE)	✓
RACE (MULTIPLE SELECTIONS REMAIN)	✓
RACE (MULTIPLE CONDENSE TO OTHER OR MULTIPLE FIELD)	
TIME PERIOD	Since 2011 or when THO joined shared EHR

205,000

2

Tribe — 2.1 — **128,000**

- 2.1.1 Federally Recognized Tribe, Corporation, or Village — **119,000**
  - **Tribe:** ATHS Native Tribes and Corporations

OR

- 2.1.2 Added new Tribes Summer 2023 and Tribe might have been listed initially or missing CIB/Tribe name from patient — **9,000**
  - **Tribe:** INDIAN-TRIBE UNSPECIFIED

OR

- 2.2 Used for Beneficiaries with Tribal identification or a Certificate of Indian Blood (CIB) or Bureau of Indian Affairs (BIA) card
  - **Eligibility Status:** PRC and DIRECT

OR

- 2.3 Benefit Code is Alaska Native / Indian
  - **Benefit Code:** ALASKA NATIVE/INDIAN

OR

- 2.4 Certificate of Indian Blood or Tribal Documentation Scanned into EHR
  - **CIB on file:** Yes

OR

Race — 2.5 — **198,000**

- 2.5.1 Race is American Indian or Alaska Native — **193,000**
  - **Race:** American Indian or Alaska Native

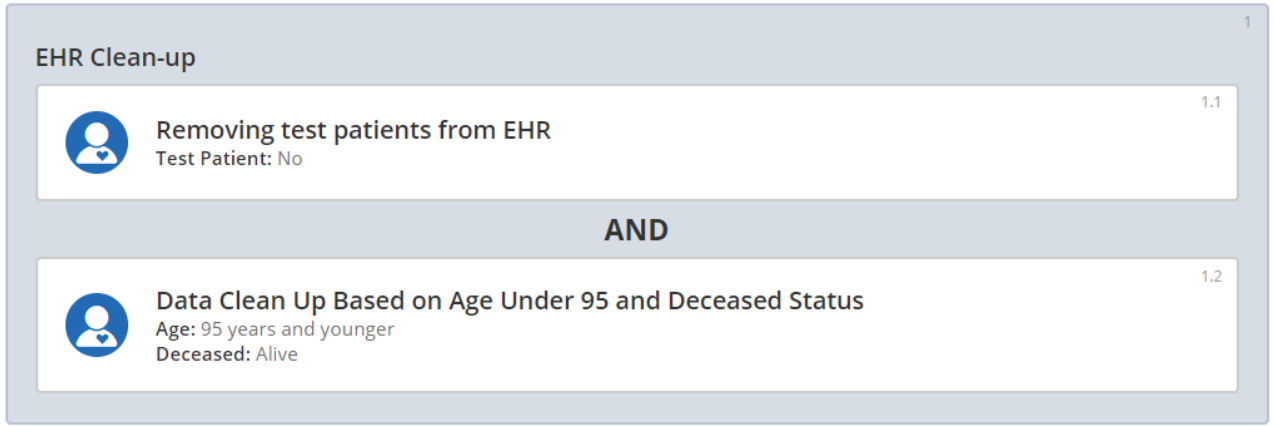
OR

- 2.5.2 Race is Multiple including American Indian or Alaska Native — **5,000**
  - **Race:** Multiple including American Indian or Alaska Native

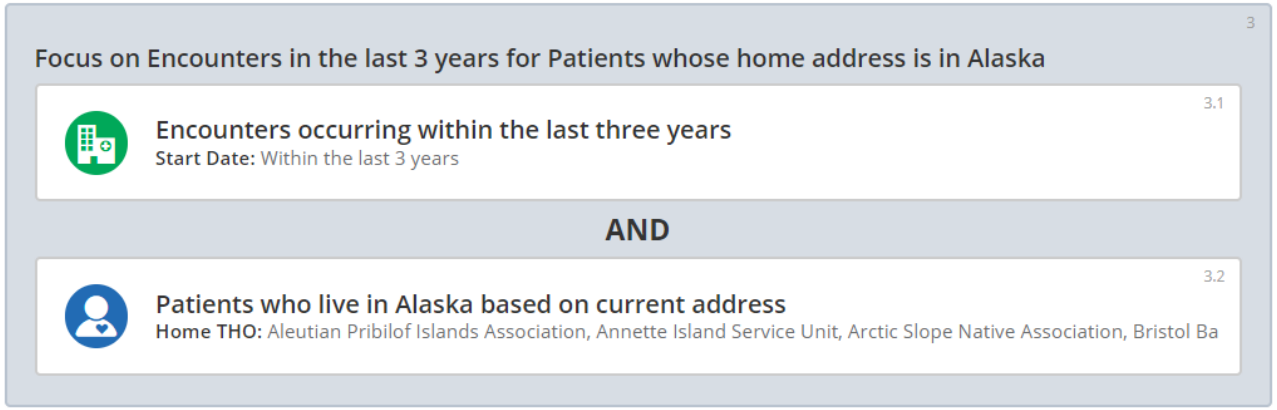
Counts included are for demonstration and have been rounded down.

Enhancing Data Quality & Use of Dashboard Filters

Considerations for Patient Mortality: We are working on enhancing the accuracy of our patient data, including loved ones who have passed away but are not documented in the EHR.



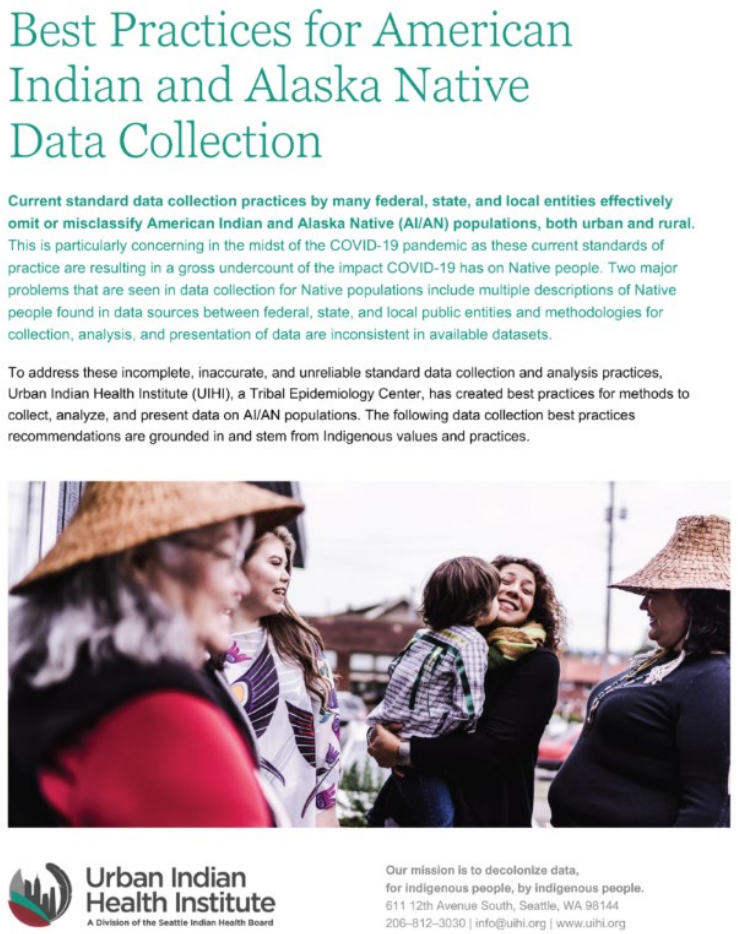
Dashboard Filters Timeframe and Home City: Within dashboards there are filters based on home city or by specifying a measurement period. As a result, these specific limitations are not included in the population definition.



ALASKA NATIVE TRIBAL HEALTH CONSORTIUM

Additional Resources

To address these incomplete, inaccurate, and unreliable standard data collection and analysis practices, Urban Indian Health Institute (UIHI), a Tribal Epidemiology Center, has created best practices for methods to collect, analyze, and present data on AI/AN populations.



Best Practices for American Indian and Alaska Native Data Collection

Current standard data collection practices by many federal, state, and local entities effectively omit or misclassify American Indian and Alaska Native (AI/AN) populations, both urban and rural. This is particularly concerning in the midst of the COVID-19 pandemic as these current standards of practice are resulting in a gross undercount of the impact COVID-19 has on Native people. Two major problems that are seen in data collection for Native populations include multiple descriptions of Native people found in data sources between federal, state, and local public entities and methodologies for collection, analysis, and presentation of data are inconsistent in available datasets.

To address these incomplete, inaccurate, and unreliable standard data collection and analysis practices, Urban Indian Health Institute (UIHI), a Tribal Epidemiology Center, has created best practices for methods to collect, analyze, and present data on AI/AN populations. The following data collection best practices recommendations are grounded in and stem from Indigenous values and practices.

Urban Indian Health Institute
A Division of the Seattle Indian Health Board

Our mission is to decolonize data, for indigenous people, by indigenous people.
611 12th Avenue South, Seattle, WA 98144
206-812-3030 | info@uihi.org | www.uihi.org

Source: Urban Indian Health Institute https://www.uihi.org/download/best-practices-for-american-indian-and-alaska-native-data-collection/

Thank you

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We extend our gratitude to the CDC for supporting a portion of the costs in defining an AN/AI population through our immunization work under the Tribal Public Health Capacity-Building and Quality Improvement Umbrella Cooperative Agreement CDC-RFA-OT18-18030301SUPP20