Health Equity Update from CMS Office of Minority Health

September 25, 2023

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

[Link: 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

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

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

Key:
● Collected aligned to 2011 HHS standards
◊ Collected with no major issues, no adopted standard
○ Collected with standards and/or completeness issue(s)
- 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. 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
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.
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
Connect with CMS OMH

Contact Us
OMH@cms.hhs.gov

Visit Our Website
go.cms.gov/omh

Listserv Signup
bit.ly/CMSOMH

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
Thank You!
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

<table>
<thead>
<tr>
<th>Lifetime Use of Services</th>
<th>Southwest Tribe, % (99% CI)</th>
<th>Northern Plains Tribes, % (99% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Combined (n = 1446)</td>
<td>Men (n = 617)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mental health professional</td>
<td>34.6 (26.4-43.7)</td>
<td>19.6 (7.8-41.2)</td>
</tr>
<tr>
<td>Medical professional</td>
<td>29.1 (21.5-38.1)</td>
<td>21.3 (8.5-44.0)</td>
</tr>
<tr>
<td></td>
<td>37.3 (28.8-49.1)</td>
<td>32.6 (15.4-56.2)</td>
</tr>
<tr>
<td>Traditional healer</td>
<td>43.9 (40.0-57.9)</td>
<td>40.6 (23.7-60.0)</td>
</tr>
<tr>
<td>Any help-seeking</td>
<td>66.6 (57.7-74.4)</td>
<td>57.1 (36.2-75.7)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Lifetime Substance Use Disorder(s) Only</th>
</tr>
</thead>
<tbody>
<tr>
<td>Combined (n = 1638)</td>
</tr>
<tr>
<td>Mental health professional</td>
</tr>
<tr>
<td>Medical professional</td>
</tr>
<tr>
<td>Traditional healer</td>
</tr>
<tr>
<td>Any help-seeking</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Lifetime Comorbid Depressive and/or Anxiety and Substance Disorders</th>
</tr>
</thead>
<tbody>
<tr>
<td>Combined (n = 1446)</td>
</tr>
<tr>
<td>Mental health professional</td>
</tr>
<tr>
<td>Medical professional</td>
</tr>
<tr>
<td>Traditional healer</td>
</tr>
<tr>
<td>Any help-seeking</td>
</tr>
</tbody>
</table>

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

CULTURE INFORMS BEHAVIOR, INCLUDING HEALTH PRACTICES

Table 2  Results from the survey by stakeholder group

<table>
<thead>
<tr>
<th></th>
<th>Participant group</th>
<th>Mothers (n=16)</th>
<th>Teens (n=14)</th>
<th>Young adults (n=22)</th>
<th>Healthcare providers (IHS and tribal) (n=10)</th>
<th>Chi-square (p value)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>HPV awareness</strong>—how familiar are you with HPV?</td>
<td>% Very familiar (n)</td>
<td>12.5% (2)</td>
<td>7.1% (1)</td>
<td>4.5% (1)</td>
<td>30.0% (3)</td>
<td>26.1 (&lt;0.005)</td>
</tr>
<tr>
<td></td>
<td>% Somewhat familiar (n)</td>
<td>43.8% (7)</td>
<td>7.1% (1)</td>
<td>45.5% (10)</td>
<td>60.0% (6)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>% Heard of it, but not familiar (n)</td>
<td>18.8% (3)</td>
<td>35.7% (5)</td>
<td>40.9% (9)</td>
<td>0.0% (0)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>% Not at all familiar (n)</td>
<td>25.0% (4)</td>
<td>50.0% (7)</td>
<td>4.5% (1)</td>
<td>0.0% (0)</td>
<td></td>
</tr>
<tr>
<td><strong>HPV knowledge (true/false questions)</strong></td>
<td>% Correctly answered true (n)</td>
<td>43.8% (7)</td>
<td>42.9% (6)</td>
<td>54.5% (12)</td>
<td>70.0% (7)</td>
<td>2.3 (0.52)</td>
</tr>
<tr>
<td>HPV is spread by sexual contact</td>
<td>% Correctly answered false (n)</td>
<td>31.3% (5)</td>
<td>7.1% (1)</td>
<td>22.7% (5)</td>
<td>30.0% (3)</td>
<td>2.9 (0.41)</td>
</tr>
<tr>
<td>HPV can cause high blood pressure</td>
<td>% Correctly answered false (n)</td>
<td>37.5% (6)</td>
<td>6.0% (0)</td>
<td>40.9% (9)</td>
<td>40.0% (4)</td>
<td>8.0 (&lt;0.005)</td>
</tr>
<tr>
<td>HPV can cause cervical cancer</td>
<td>% correctly answered true (n)</td>
<td>68.8% (11)</td>
<td>28.6% (4)</td>
<td>86.4% (19)</td>
<td>70.0% (7)</td>
<td>13.0 (&lt;0.005)</td>
</tr>
<tr>
<td>HPV is a rare infection</td>
<td>% Correctly answered false (n)</td>
<td>37.5% (6)</td>
<td>6.0% (0)</td>
<td>40.9% (9)</td>
<td>40.0% (4)</td>
<td>8.0 (&lt;0.005)</td>
</tr>
<tr>
<td>HPV can cause genital warts</td>
<td>% Correctly answered true (n)</td>
<td>75.0% (4)</td>
<td>14.3% (2)</td>
<td>40.9% (9)</td>
<td>50.0% (5)</td>
<td>4.6 (0.30)</td>
</tr>
<tr>
<td>HPV can cause abnormal Pap smears</td>
<td>% Correctly answered true (n)</td>
<td>50.0% (8)</td>
<td>7.1% (1)</td>
<td>45.5% (10)</td>
<td>70.0% (7)</td>
<td>10.7 (&lt;0.05)</td>
</tr>
</tbody>
</table>

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

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)

“[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

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

Schools

Tribal Programs

Indian Health Service

Leaders

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

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. Culture Centeredness

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

2. Cultural Practices

3. Support Relationships
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 gentleness 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

- Establishing collaborations
- Data ownership (IRB)
- Allocation of funds
- Timelines
- Research design/Rigor
- Product form and audience

Institutional Regulations (Universities, Funding Agencies)
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

RESOURCES

Thank you!

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(Mandan – Hidatsa)  
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(Colville)  
Clinical Psychologist, Colville Behavioral Health  
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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
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
1. The legal context & background of “we are more than numbers”
Corporations and Villages in Alaska

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.

<table>
<thead>
<tr>
<th>Tribe</th>
<th>Village Corporation</th>
<th>Regional Corporation</th>
</tr>
</thead>
</table>
| Of the 574 federally recognized Tribal Nations, 229 are located in Alaska | • Little Shell Tribe of Chippewa Indians, Tribal Member  
• Blackfeet Nation, Descendant | Not Applicable                  |
| Native Village of Tanana, Tribal Member | Tozitna Limited, Descendant of Shareholder | Doyon Limited, Shareholder |

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

1897
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.”)

1921
42 U.S.C. §§ 201 et seq. Alaska Native Health Service transferred to Division of Indian Health

1954
25 U.S.C. §§ 5301 et seq. (Indian Self-Determination and Education Assistance Act) Authorized Indian Tribes to operate IHS programs and later compact

1975
25 U.S.C. §§ 1601 et seq. (Indian Health Care Improvement Act and Declaration) explaining trust responsibility and legal obligations to Indians

1976
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
Tribal Affiliation Documentation Examples

- **Tribal Nation ID Card**
- **Tribal Letter**
- **Bureau of Indian Affairs Form or Card**
- **ANSCA Documentation**
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. These 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

© 2018 Slide Adapted from Health Catalyst
The ATHS AN/AI definition includes information from 5 registration fields.

Excluded Fields from AN/AI: Blood Quantum for IHS user definition and use Tribal Enrollment or Descendant for TSHIP enrollment periods.
2. Which definitions are widely used for AN/Al population?
Definitions of AI/AN population vary by authority for Alaska

**POPULATION ESTIMATE:**

- **User Population 2022:** 159,541
- **Census AI/AN In Combination 2020:** 160,287
- **Census AI/AN Alone 2020:** 111,575

**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)**

**Atheneum Health Science (AHS) Operational Spring 2023:** 205,000
**Review: Methods for Defining Alaska Native and American Indian People**

Methods are based on current understanding and publicly available information.

<table>
<thead>
<tr>
<th>ORGANIZATION</th>
<th>TRIBE</th>
<th>ELIGIBILITY STATUS</th>
<th>BENEFIT CODE</th>
<th>BLOOD QUANTUM</th>
<th>RACE (ALONE)</th>
<th>RACE (MULTIPLE SELECTIONS REMAIN)</th>
<th>RACE (MULTIPLE CONDENSE TO OTHER OR MULTIPLE FIELD)</th>
<th>TIME PERIOD</th>
</tr>
</thead>
<tbody>
<tr>
<td>IHS</td>
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<td>✓</td>
<td>✓</td>
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<td>✓</td>
<td>✓</td>
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<td></td>
</tr>
<tr>
<td>US Census</td>
<td>✓</td>
<td></td>
<td>✓</td>
<td></td>
<td>✓</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HRSA (UDS)</td>
<td>✓</td>
<td></td>
<td>✓</td>
<td></td>
<td>✓</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ANTHC &amp; ATHS</td>
<td>✓</td>
<td></td>
<td>✓</td>
<td></td>
<td>✓</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

- **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

### 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

<table>
<thead>
<tr>
<th>ORGANIZATION</th>
<th>IHS</th>
</tr>
</thead>
<tbody>
<tr>
<td>POPULATION IN ALASKA SERVICE AREA</td>
<td>159,541</td>
</tr>
<tr>
<td>TRIBE</td>
<td>✔</td>
</tr>
<tr>
<td>ELIGIBILITY STATUS</td>
<td>✔</td>
</tr>
<tr>
<td>BENEFIT CODE</td>
<td>✔</td>
</tr>
<tr>
<td>BLOOD QUANTUM</td>
<td>✔</td>
</tr>
<tr>
<td>RACE (ALONE)</td>
<td></td>
</tr>
<tr>
<td>RACE (MULTIPLE SELECTIONS REMAIN)</td>
<td></td>
</tr>
<tr>
<td>RACE (MULTIPLE CONDENSE TO OTHER OR MULTIPLE FIELD)</td>
<td></td>
</tr>
<tr>
<td>TIME PERIOD</td>
<td>3 year inclusion (Oct 1 – Sep 30)</td>
</tr>
</tbody>
</table>
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*)

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)

*Note: IHS does not disclose specific funding calculations
IHS: Nationwide counts of Active Patients utilizing Tribal Health Systems

Total IHS User Population
FY 2022: 1,649,426

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

**AN/AI IN COMBINATION IN ALASKA (2020)**

- Eligibility Status
- Benefit Code
- Blood Quantum
- Race (Alone)
- Race (Multiple Selections Remain)
- Race (Multiple Condense to Other or Multiple Field)
- Time Period

### Separate Race Question

7. What is this person’s race?
Mark X one or more boxes AND print origins.

- White — Print, for example, German, Irish, English, Italian, Lebanese, Egyptian, etc.
- Black or African Am. — Print, for example, African American, Jamaican, Haitian, Nigerian, Ethiopian, Somali, etc.
- Irish and German
- Nigerian
- 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

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

- Blackfeet Tribe and Doyon

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**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/
## US Census Bureau: Dissemination of demographic data

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

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.


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/Al status is a legal and political description that is based on the federal trust responsibility.
Example: New Zealand 2023 Census

8 Which ethnic group do you belong to?
Mark the space or spaces which apply to you.
- New Zealand European
- Māori
- Samoan
- Cook Islands Māori
- Tongan
- Niuean
- Chinese
- Indian
- other, eg DUTCH, JAPANESE, TOKELAUMAN. Please state:

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) of the region(s)/rohe of your iwi:

https://www.census.govt.nz/what-questions-are-in-the-2023-census/
HRSA: AN/AI reporting for the Uniform Data System (UDS)

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.*
### Table 3B: Patients by Race and Hispanic, Latino/a, or Spanish Ethnicity

<table>
<thead>
<tr>
<th>Line</th>
<th>Patients by Race</th>
<th>UDS Calendar Year 2022</th>
<th>Patients in AK</th>
<th>% of Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>1a</td>
<td>Asian Indian</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1b</td>
<td>Chinese</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1c</td>
<td>Filipino</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1d</td>
<td>Japanese</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1e</td>
<td>Korean</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1f</td>
<td>Vietnamese</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1g</td>
<td>Other Asian</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Total Asian (Sum Lines 1a+1b+1c+1d+1e+1f+1g)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2a</td>
<td>Native Hawaiian</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2b</td>
<td>Other Pacific Islander</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2c</td>
<td>Guamanian or Chamorro</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2d</td>
<td>Samoan</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Total Native Hawaiian/Other Pacific Islander (Sum Lines 2a+2b+2c+2d)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Black/African American</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td><strong>American Indian/Alaska Native</strong></td>
<td></td>
<td>39,848</td>
<td>41.45%</td>
</tr>
<tr>
<td>5</td>
<td>White</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td><strong>More than one race</strong></td>
<td></td>
<td>2,561</td>
<td>2.66%</td>
</tr>
<tr>
<td>7</td>
<td>Unreported/Chose not to disclose race</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Total Patients (Sum of Lines 1 + 2 + 3 to 7)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>


3. Alaska Tribal Health System Operational Definition and the foundation of Population Health
Hypothetical Example Population of 35,000

<table>
<thead>
<tr>
<th>Screened for CRC</th>
<th>Under count AN/AI 5,000</th>
<th>Over count AN/AI 5,000</th>
</tr>
</thead>
<tbody>
<tr>
<td>20,000</td>
<td>30,000</td>
<td>40,000</td>
</tr>
</tbody>
</table>

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

**ORGANIZATION**
ANTHC & ANMC

**PATIENTS REPORTING IN ALASKA PROGRAMS**
205,000

**TRIBE**
Yes

**ELIGIBILITY STATUS**
Yes

**BENEFIT CODE**
Yes

**BLOOD QUANTUM**

**RACE (ALONE)**
Yes

**RACE (MULTIPLE SELECTIONS REMAIN)**
Yes

**RACE (MULTIPLE CONDENSE TO OTHER OR MULTIPLE FIELD)**

**TIME PERIOD**
Since 2011 or when THO joined shared EHR

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.
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.

Thank you

Rachael Mis tahks ah ki DeMarce, MPH, MPA, Little Shell Tribe and Blackfeet Nation Analytics Engagement Manager rwdemarce@anthc.org

Ben Han Lead Analytics Architect bshan@anthc.org

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