

Race and Ethnicity:

The Importance of Standardized Data Collection and Management

HL7 Booth 138

Wednesday, April 19, 2023

4:10pm - 4:40pm CT



In Person Audience Poll

OBSTETRICS RISK ASSESSMENT

All questions contained in this questionnaire are strictly confidential and will become part of your medical record.

Complete and fax this form to: [REDACTED]

Date Assessment Completed:					
Patient Demographics					
Patient Name				Insurance ID/ Medicaid #:	
Last:		First:		M.I.:	DOB:
Street Address:			City:	State:	Zip Code:
Home Phone:				Cell Phone:	
Race/Ethnicity:		<input type="checkbox"/> African American <input type="checkbox"/> Caucasian <input type="checkbox"/> Native American <input type="checkbox"/> Asian <input type="checkbox"/> Multi-Racial <input type="checkbox"/> Hispanic <input type="checkbox"/> Other		Primary Language	<input type="checkbox"/> English <input type="checkbox"/> Spanish <input type="checkbox"/> Other _____

Entities involved in Race and Ethnicity Data



1. Organizations involved in establishing “the standards”.

- Content experts: US and state government, vendors, community interest groups, providers
- Vocabulary: CDC (PHIN VAD), National Library of Medicine (NLM), LOINC, SNOMED
- Interested parties: NCQA, payers, vendors, providers
- HL7 Community involved in Race, Ethnicity, Sex, and Gender:
 - Management Groups: US Realm, Terminology Steering Committee, V2, CDA, FHIR
 - Product Families: FHIR, CDA, and V2
 - Work Groups: Cross-Groups Projects, Patient Care, Structured Documents, Vocabulary
 - Project/Accelerators: Da Vinci, Gravity, Gender Harmony, HELOIS

Code Systems and Value Set



JIRA Key	Summary	Current Status
UP-259	Update to Race valueSet in THO	Waiting for addition of CDC RE Code System to THO
UP-260	Update Ethnicity valueSet in THO	Waiting for addition of CDC RE Code System to THO
UP-261	Update valueSet definitions for Race subset valueSets in THO	Waiting for addition of CDC RE Code System to THO
UP-262	Update value set definitions for Ethnicity subset value sets in THO	Waiting for addition of CDC RE Code System to THO
UP-263	Deprecate the (HL7) Race Code System in THO	Proposal Implemented
UP-264	Deprecate the TribalEntityUS Code System in THO	Retracked-Change not needed
UP-265	Deprecate the Ethnicity Code System in THO	Proposal Implemented

2. CodeSystem(s) and ValueSets (answer lists) to be used.

- Tribal Affiliation USCDI V3 (No Code System is specified by ONC)
- HL7: Tribal Entity code system
- Use and meaning of 2131-1 “other race”
- NCQA “two or more races”
- HHS’s American Community Survey used by OMH and referenced by CMS
 - No code in the CDCREC Code system: 1) “Other Asian” 2) “Another

Structural Organization:

3. Data elements and structural representations to be used.

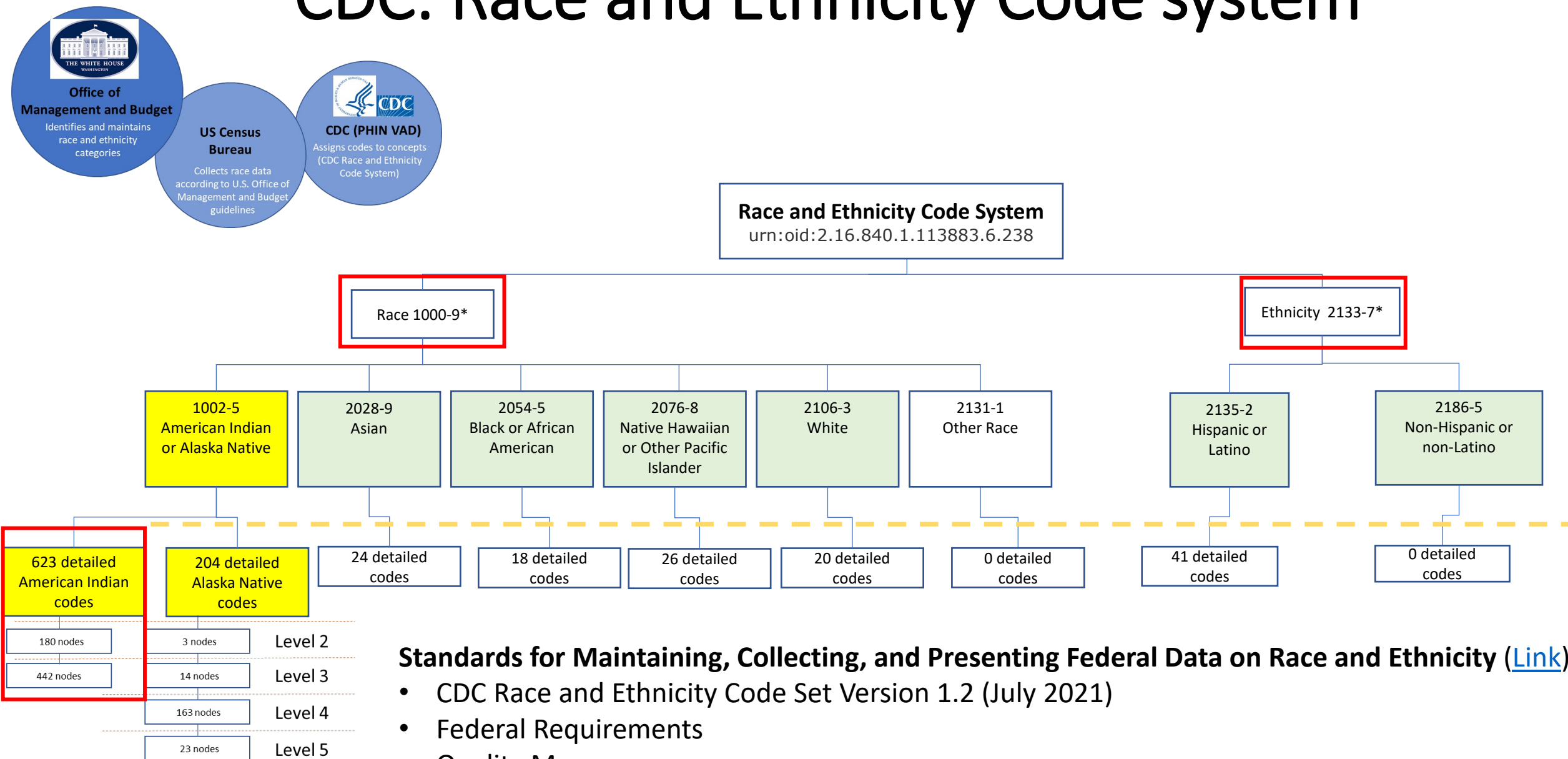


US Core Implementation Guide
6.0.0-ballot - STU6 Ballot U



2.

CDC: Race and Ethnicity Code system



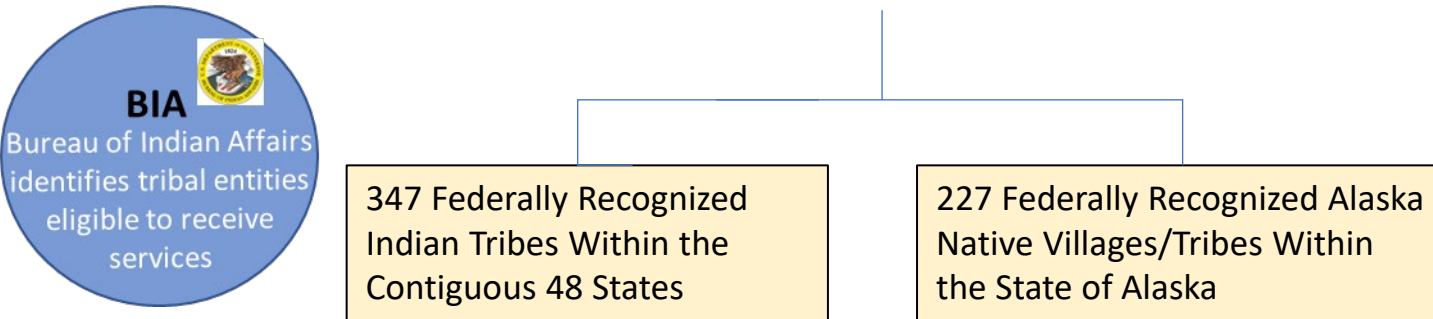
Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity ([Link](#))

- CDC Race and Ethnicity Code Set Version 1.2 (July 2021)
- Federal Requirements
- Quality Measures

2.

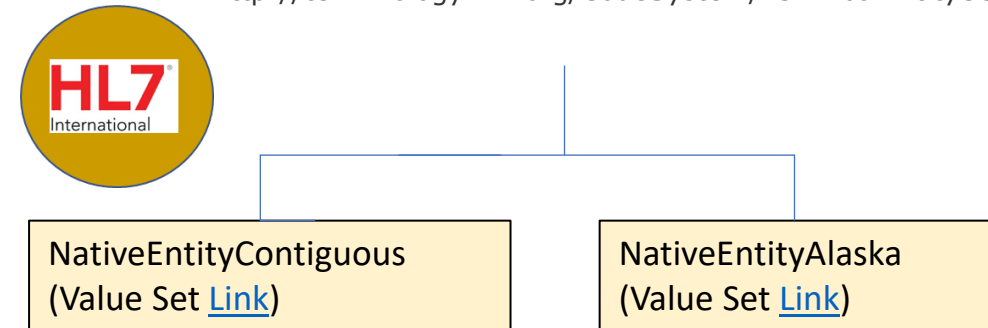
Federal and Registered Notice by Indian Affairs Bureau and HL7 Tribal Entity Code System

Indian Entities Recognized by and Eligible To Receive Services From the United States Bureau of Indian Affairs
(Indian Tribes within the contiguous 48 states and Alaska)



**HL7 Code System
TribalEntityUS**

Official URL:
<http://terminology.hl7.org/CodeSystem/v3-TribalEntityUS>



Indian Entities Recognized by and Eligible To Receive Services From the United States Bureau of Indian Affairs ([Link](#))

- Current list of 574 Tribal entities recognized by and eligible for funding and services from the Bureau of Indian Affairs (BIA) by virtue of their status for as Indian Tribes
- HL7 Terminology (THO) has a code system [TribalEntityUS](#).
- Limited hierarchical structure
- A process to maintain alignment of HL7 TribalEntityUS Code System and the Federal Regulations are being finalized.

Structural organization: Modeling in Gravity (draft), US Core, and Gender Harmony

Gravity

(<http://hl7.org/fhir/us/sdoh-clinicalcare/STU2/StructureDefinition-SDOHCC-ObservationRaceOMB.html>)

- Use of Observation Profiles (SDOHCC Observation Race and SDOHCC Observation Ethnicity) **Includes data elements: performer, method, derivedFrom**
- Multiple invariant rules to ensure proper data population (i.e., Must have either a dataAbsentReason or at least one of the defined race components but not both)
- dataAbsentReason - Uses a full range of dataAbsentReasons rather than “unknown” or “asked but refused to answer” Null Flavors as part of Race & Ethnicity valueSet
- Use of a string to capture 0..1 Race description for “other race” write-in (same for Ethnicity)

US Core

(<http://hl7.org/fhir/us/core/2023Jan/index.html>)

- Use of extension in [Patient Profile](#) (us-core-race and us-core-ethnicity)
 - If target is a Patient resource (USCorePatientProfile) then the details in the Provenance resource apply to all aspects of the Patient resource (i.e., not race alone)
- January 2023 Ballot use of Observation “[Screening and Assessment](#)”
 - [US Core Observation Screening Assessment Profile](#)
 - [US Core Simple Observation Profile](#)

Gender Harmony

- To be Determined

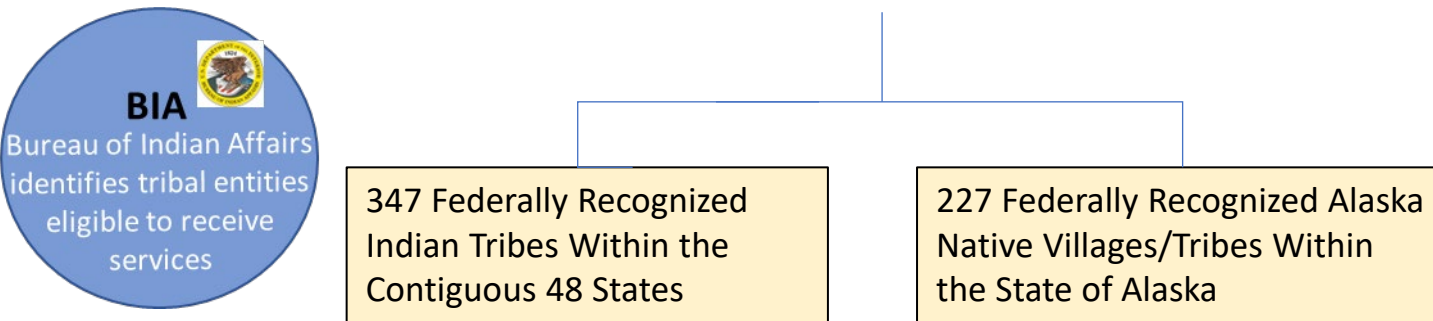
Learnings To Date

- Live participant surveys:
 - Half of the individuals do not understand the details of OMB 5 + 2
 - For the individuals that understood details of OMB 5 + 2 recently experienced a survey that was not consistent with OMB 5 + 2
- There is interest in improving the consistency of standard data representation for race and ethnicity information across all HL7 products.
- Potential Changes coming for the Race and Ethnicity Code System
 - CDC has plans to release a new Code System for Race and Ethnicity
 - OMB is seeking comments on potential changes for Race and Ethnicity Value Sets
 - Tribal Affiliation data element should use the HL7 Code System for Tribal Entities, not the CDC Race codes for American Indian
- There is a need to coordinate federal activities.
- There is support from the community to use both Observation and Patient Resource to capture race and ethnicity provenance detail.

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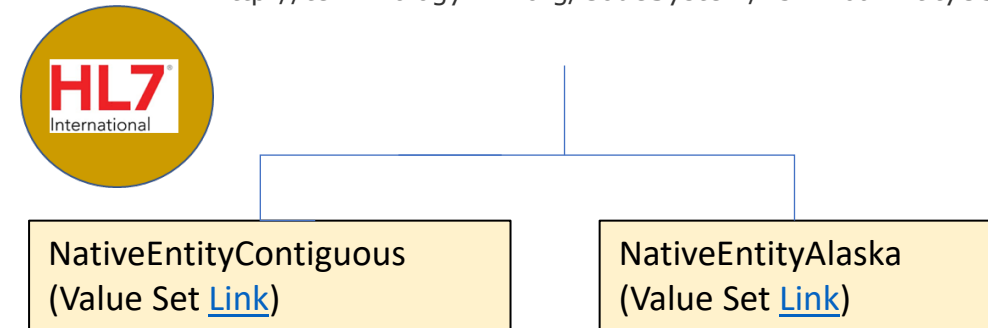
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Addressing Health Equity with HEDIS



GOALS

- **Bring transparency** to inequities in health care quality.
- **Promote inclusive approaches** to measurement and accountability.
- **Address social risks** to improve health outcomes.
- **Incentivize equity** with benchmarks and performance scoring.

TEAMING UP WITH NCQA

HEDIS[®] stratifies measures by race & ethnicity, with more to come

HEDIS MY 2022

Prevention & Screening

Colorectal Cancer Screening

Cardiovascular

Controlling High Blood Pressure

Diabetes

Hemoglobin A1c Control for Patients With Diabetes

Access and Availability of Care

Prenatal and Postpartum Care

Utilization

Child and Adolescent Well Care Visits

HEDIS MY 2023

Prevention & Screening

Immunizations for Adolescents

Breast Cancer Screening

Respiratory

Asthma Medication Ratio

Behavioral Health

Follow-Up After Emergency Department Visits for Substance Use

Pharmacotherapy for Opioid Use Disorder

Access and Availability of Care

Initiation and Engagement of Substance

Use Disorder Treatment

Utilization

Well-Child Visits in the First 30 Months of Life

Implementing Race/Ethnicity Stratification

Ethnicity:

- Hispanic / Latino
- Not Hispanic / Latino
- Asked but No Answer
- Unknown

Race:

- American Indian or Alaskan Native
- Asian
- Black or African American
- Native Hawaiian or Other Pacific Islander
- White
- Some Other Race
- **Two or More Races**
- Asked but No Answer
- Unknown

Categories

Race and ethnicity are reported separately.

For each race and ethnicity category, plans must also report the breakdown by data source.

Direct:

Member Self-Reported Data

Indirect:

Secondary or Imputed Data

Debate exists over allowing this answer where OMB 5 should be collected.

Source data should not include the concept “two or more Races”. This is a derived concepts that makes stratification possible.

Post-Presentation Audience Poll

OBSTETRICS RISK ASSESSMENT

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Patient Demographics					
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Last:		First:		M.I.:	DOB:
Street Address:			City:	State:	Zip Code:
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Race/Ethnicity:	<input type="checkbox"/> African American <input type="checkbox"/> Caucasian <input type="checkbox"/> Native American <input type="checkbox"/> Asian <input type="checkbox"/> Multi-Racial <input type="checkbox"/> Hispanic <input type="checkbox"/> Other			Primary Language	<input type="checkbox"/> English <input type="checkbox"/> Spanish <input type="checkbox"/> Other _____

Multi-Stakeholder Approach is Needed

- Watch for new HL7 Blog Post
- May HL7 WGM+ Birds of a Feather, Wednesday Lunch
- New Reagan-Udall RAISE Accelerator
- Gravity Project
- US Core FHIR IG
- Consolidated CDA Companion Guide
- TSMG – CodesSystem and ValueSet clean-up, harmonization
- CMG – CDA RecordTarget extensions to align with FHIR Patient Resource

Links:

Raise Accelerator

- <https://reaganudall.org/programs/research/raise>

Gravity Project

- <https://www.hl7.org/gravity/>

Gender Harmony

- <https://confluence.hl7.org/display/VOC/The+Gender+Harmony+Project>

The Standard (The Official Blog of Health Level Seven® International)

- <https://blog.hl7.org/>

Questions ?



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