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]

### Patient Demographics

| Patient Name | Insurance ID/Medicaid #:
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<td>Last:</td>
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**Home Phone:**

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<td>Caucasian</td>
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<td>Asian</td>
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<tr>
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<td>Hispanic</td>
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<td>Other</td>
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**Cell Phone:**

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<th>Primary Language:</th>
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<tr>
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**Other Language:**

[Redacted]
1. Organizations involved in establishing “the standards”.

- Content experts: US and state governments, 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

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

Tribal Affiliation USCDI V3 (No Code System is specified by ONC)

- 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 Hispanic…”
- Rollup of “Mexican” concept is incomplete

3. Data elements and structural representations to be used.

Structural Organization:
- Representation
- Hierarchy
- Perfromer (source) and method
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
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)

- 347 Federally Recognized Indian Tribes Within the Contiguous 48 States
- 227 Federally Recognized Alaska Native Villages/Tribes Within the State of Alaska

HL7 Code System 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.
Gravity

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

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HL7 Code System TribalEntityUS

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• A process to maintain alignment of HL7 TribalEntityUS Code System and the Federal Regulations are being finalized.
3. Structural organization: Modeling in Gravity (draft), US Core, and Gender Harmony

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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

**Categories**

Race and ethnicity are reported separately.

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

**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

**Ethnicity:**
- Hispanic / Latino
- Not Hispanic / Latino
- Asked but No Answer
- Unknown

- **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 concept that makes stratification possible.
# OBSTETRICS RISK ASSESSMENT

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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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