Race and Ethnicity:
Problem Statement

Race and Ethnicity information is collected and communicated inconsistently in the United States of America.
### Informed Consent for Immunization with Inactivated Vaccine

**Patient Ethnicity**

I consider myself: * ☐

**Patient Race**

Which of the following racial designations best describes you (select one or more): * ☐

- ☐ American Indian or Alaska Native
- ☐ Asian
- ☐ Black or African American
- ☐ Native Hawaiian or Other Pacific Islander
- ☐ White
- ☐ Prefer not to disclose
Entities involved in Race and Ethnicity:

- **Office of Management and Budget** identifies and maintains race and ethnicity categories.
- **US Census Bureau** collects and publishes data on race and ethnicity.
- **CDC (PHIN VAD)** shares data on race and ethnicity in healthcare.
- **Vocabulary** includes CDC (PHIN VAD), National Library of Medicine (NLM), LOINC, SNOMED.
- **Interested parties** include NCQA, payers, vendors, providers.
- **HL7 Community** involved in Race, Ethnicity, Sex, and Gender:
  - Management Groups: US Realm, Terminology, Ethnicity, Sex, and Gender
  - Product Families: FHIR, CDA, and V2
  - Work Groups: Cross-Groups Projects, Patient Care, Structured Documents, Vocabulary
  - Project/Accelerators: Da Vinci, Gravity, Gender Harmony

Code Systems and Value Sets:

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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 Hispanic...”
  - Rollup of “Mexican” concepts is incomplete

Structural Organization:

- **Representation**
- **Hierarchy**
- **Source and method**
Background for Race and Ethnicity:

Entities Involved
Code Systems and Values Sets
Structural Organization
Entities Involved
The Office of Management and Budget is responsible for identifying minimal categories (OMB 5+2). They work with the US Census Bureau to update concepts and codes for minimal categories and more detailed concepts.

CDC coordinates with the US Census Bureau to update and assign codes for race and ethnicity concepts.

HL7 and HHS’s Office of the National Coordinator for HIT work very closely together to coordinate USCDI and implementation guides.

The work in these communities is instrumental in how healthcare details are collected and shared across organizations.
Codes Systems and Value Sets
**Use of CDC Code Systems in HL7 Community**

**STEP 1: Create a Permanent url for each Code System and Value Set**

**Action:** CDC defines permanent url that is a human-readable browsable location for each code system and value set
- The url is used in an IG to display content
- HL7 will support FHIR IG Publishing system to reference CDC permanent url
- Improves usability and access to source of truth
- Provides source of truth from the authoritative source
  - Initially may be only human readable
  - Eventually would allow access to downloadable copies of CodeSystem and ValueSet Resources

**STEP 2: Accessible Convenience Copy**

**Action 1:** Establish an agreement between CDC and HL7 granting permission for code System use
**Action 2:** Add CodeSystem to HL7 Terminology (THO) using UTG process to make CDC Code System viewable/usable in HL7 IGs
  - Identify “responsible party” to perform terminology work
    - **It would be best if CDC created verified file**
    - Load Code System into THO and support QA
  - CDC Code System would be identified as an External Complete Code System in THO and “hidden” copies would not be used

**Updating:**
- CDC would provide HL7 an updated FHIR CodeSystem Resource (i.e., JSON file) when changes are made
- HL7 “responsible party” updates convenience copy using THO/UTG Process

**STEP 3: FHIR API Access**

**Action:** CDC stands up a FHIR terminology server endpoint to provide FHIR API access to code systems and value sets

**Updating:**
- Updating the Code System requires no additional manual steps
Based on feedback from CDC’s Dan Pollock. It is anticipated that CDC will introduce additions and retire concepts to the Race and Ethnicity code system. In addition, he stated

“The plan is to publish new identifiers for each concept in the Code System, which will be published as a stand alone work product that is supplemented by the separate mapping table. That table will provide the corresponding concept and unique identifier that was first published over 20 years ago.”

This statement is of concern if it leads to the development of new codes for current concepts.
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HHS’s American Community Survey used by OMH and referenced by CMS

No code in the CDCREC Code system:
- Race: “Other Asian”
- Ethnicity: “Another Hispanic…”

Rollup of “Mexican” concepts is incomplete:
- 2148-5 Mexican
- 2149-3 Mexican American
- 2150-1 Chicano
- 2152-7 La Raza
- 2153-5 Mexican American Indian

Consider:
- Remove “Mexican American, Chicano/a”
- Add (e.g., Mexican American, Chicano/a, La Raza, etc.)
Structure alignment of American Community Survey with CDCREC Code System (Hierarchy)

Race and Ethnicity Code System
urn:oid:2.16.840.1.113883.6.238

Key:
- Complete alignment with CDCREC display name
- No alignment with CDCREC display name
  - Red = ACA display name is different than CDCREC Display name
- ACA 834 currently has combined three data elements to a single code of 2148-5 Mexican
  - * = Code not used in ACA

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Race and Ethnicity Code System
urn:oid:2.16.840.1.113883.6.238

1002-5 American Indian or Alaska Native:
There is a subgrouping is “American Indian” and “Alaska Native” with multiple levels of details.

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

1002-5 American Indian or Alaska Native

1004-1 American Indian (622 detailed codes)
1735-0 Alaska Native (203 detailed codes)

Level 1
- 180 nodes
- 3 nodes

Level 2
- 442 nodes
- 14 nodes

Level 3
- 163 nodes
- 23 nodes

Level 4

Level 5

- HL7 Terminology (THO) has a code system for TribalEntityUS.
- The concepts represented in THO are not current with the Federal Regulations (1/28/22).
- The United States Core Data for Interoperability (USCDI) added the data element “Tribal Affiliation” to Version 3.
- While Applicable Vocabulary Standard(s) were not identified in USCDI v3, there was support to use HL7 THO codes to represent concepts.
- The HL7 FHIR® Implementation Guide: Electronic Case Reporting (eCR) - US Realm uses the “TribalEntityUS” value set derived from the HL7 “TribalEntityUS” code system
Structural Orientation

Representation

Hierarchy

Source and method
<table>
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<tr>
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<th>Description &amp; Constraints</th>
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<td>us-core-race</td>
<td></td>
<td>0..1</td>
<td>Complex</td>
<td>Health care services for use of a specific race category.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>US Core Race Extension URL: <a href="http://hl7.org/fhir/us/core/StructureDefinition/us-core-race">http://hl7.org/fhir/us/core/StructureDefinition/us-core-race</a></td>
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- **extension:ombCategory** 0..5 Extension
  - **url** 1..1 uri
  - **value[x]** 1..1 Coding

- **extension:detailed** 0..* Extension
  - **url** 1..1 uri
  - **value[x]** 1..1 Coding

- **extension:text** 1..1 Extension
  - **url** 1..1 uri
  - **value[x]** 1..1 string

**Binding:** OMB Race Categories (required): The 5 race category codes according to the OMB Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity, Statistical Policy Directive No. 15, as revised, October 30, 1997.

**Binding:** Detailed Race (required): Extended race codes.

**Binding:** Race Text (required): Race Text.
Provenance: Current problem

• Information in a Provenance resource is applied to the entire referenced resource (Provenance.target)
  • 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)
  • To isolate provenance information for a single data element in a Patient resource, that information may need to be represented in an Observation resource referenced by an appropriate Provenance resource or with provenance details capture in the Observation

http://hl7.org/fhir/R4/provenance.html
Multiple invariant rules to ensure proper data population

performer:
derivedFrom:
method:

- Self-reported
- Reported By Related Person
- Administrative
- Derived Specify
- Observed
- Unknown

dataAbsentReason:

- Unknown
- Asked But Unknown
- Temporarily Unknown
- Not Asked
- Asked But Declined
- Masked
Background Framing: Conclusion
Entities involved in Race and Ethnicity:

- Content experts: US and state governments, vendors, community interest groups, providers
- Vocabulary: CDC (PHIN VAD), National Library of Medicine (NLN), 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

Entities Engaged in Collecting, Sharing, and Using Race and Ethnicity Data:

- Promulgates a set of uniform data collection standards for inclusion in surveys conducted or sponsored by HHS as required by section 410 of the Information Act.
- American Community Survey used by OMB and referenced by CMS. Introduced 3 variants in the codes used to identify race and ethnicity concepts.
- Multiple states have their own logic for these concepts.

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Next Steps

Birds of Feather: Race and Ethnicity
Maryland Ballroom C
12:30-1:30