An Assessment of the Availability and Quality of Race and Ethnicity Data Submitted to The Maine Health Data Organization

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Objective

This analysis offers insight into the quality and availability of race and ethnicity data collected across two critical healthcare data sources in the MHDO's All-Payer Claims Data (APCD), which includes records on 91% of Maine's insured population; and the Hospital Encounter Data, encompassing 69% of Maine's population.

Our assessment aims to improve the collection of race and ethnicity information, as well as support efforts to address health inequities.

Background

In 1977, the Office of Management and Budget established a minimum standard for the collection of race and ethnicity information for federal surveys[1]. These standards include:

- Self-reported
- Multiple selections
- 5 racial groups (American Indian or Alaskan Native, Asian, Black, Native Hawaiian or Pacific Islander, and White)
- 2 ethnic groups (Hispanic and non-Hispanic)

Our analysis builds on efforts to assess progress toward collecting these data in Maine, codified in Public Law 2021 Chapter 34,[2] and aims to understand the impact of differences in data submission requirements at the individual-level.

Notes on MHDO Data Source

All-Payer Claims Data (APCD) includes medical, pharmacy, and dental claims data from commercial and public payers. Race and ethnicity data was a required element for eligibility records starting with 2021 submissions to MHDO, and allows inclusion of up to three race categories, three ethnicity categories, and a Hispanic indicator.

Hospital Inpatient and Outpatient Encounter Data includes all inpatient and outpatient services of the hospital and services provided by hospital-owned specialty groups or primary care practices. Race and ethnicity information has been largely reported to MHDO by Maine hospitals for over a decade. It allows inclusion of one race value and one ethnicity value, with additional options for race refused, race unknown, and ethnicity unknown.

Populations Studied

Data from the MHDO APCD was based on month-level records from medical, dental, and pharmacy data for 2021. Data from the MHDO Hospital Encounter data was based on inpatient and outpatient hospital visits with a discharge date between 2018 and 2021.

Study Design

Using a deidentified index key (or PersonID) at the individual level, data in the MHDO APCD database was linked to MHDO Hospital Encounter data. Data availability and completeness was assessed and consistency for deidentified individuals was examined within and across data sources.

Consistency is defined as a deidentified PersonID having the same race(s) 100% of the time after 'unknown' or 'refused to answer' options are eliminated. Since the Hospital Encounter submission layout does not currently have options to include multiple races, calculation was modified so at least one of the race options matched 100% of the time among individuals with multiple races included in the APCD.

Limitations & Implications

Although there is a large proportion of deidentified individuals with consistent data across data sources, this analysis was based on limited information from payers in the APCD database. Data collection practices from payers is unknown at this time, so it is difficult to determine if gaps in the availability of racial categories is related to data reporting or data collection standards from commercial and public payers.

When assessing racial and ethnic disparities, understanding data quality that is being used to examine demographic characteristics is essential. Systems should collect and offer the ability to submit data based on the OMB or CDC standards with options to include multiple races.

For healthcare data sources submitted to MHDO, this and prior assessments will support development of a comprehensive deidentified PersonID dataset to assist MHDO authorized data users by providing person-level demographic attributes, and transparent documentation on the processing rules used to obtain these person-level attributes.

Principal Findings

Across MHDO Data Sources

- **92%** Consistent Race (n=442,429)
- **98%** Consistent Ethnicity (n=435,939)
- **91%** Consistent Race & Ethnicity (n=435,871)

MHDO Dataset Comparison to OMB Standards

OMB Standards

Race options:
- American Indian or Alaska Native (AI AN)
- Asian
- Black or African American
- Native Hawaiian or Pacific Islander (NH PI)
- White

Ethnicity options:
- Hispanic
- Non-Hispanic

Standards:
- Race information includes and/or rolls up to 5 response options
- Ethnicity information includes and/or rolls up to 2 response options
- Self-reported race and ethnicity
- Ability to report two or more races, if applicable

	MHDO Hospital Encounter Data (Implemented March 1, 2007)	MHDO All-Payer Claims Database (Implemented January 1, 2021)
Race has 5 OMB response options + 'Other Race'[1]	✓	✓
Ethnicity has 2 OMB response options	✓	✓
Self-reported race and ethnicity*	✓	✓
Able to include two or more races, if applicable	✗	✓

*MHDO has information from data submitters that race and ethnicity are self-reported by patients completing an intake form, or members completing an enrollment form.

% Individuals with Race or Ethnicity

	Alone	Combined
APCD (n = 1,488,661)	36%	79%
Hospital (n = 1,410,768)	98%	99%

Conclusions

Less than half of the people in the MHDO APCD have race or ethnicity information available (36%), of which a majority comes from Medicaid data (76%).

Linking across MHDO data sources to obtain supplemental demographic information appears to be a reliable and feasible approach.

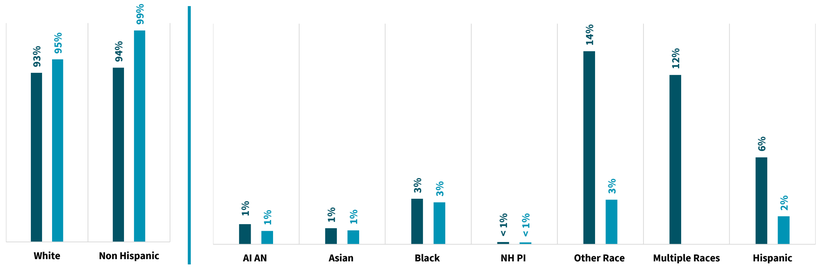
Data was consistent for individuals within and across MHDO data sources, suggesting data accuracy; however, there appears to be differences when looking at specific racial groups with less consistency among Native Hawaiian or Pacific Islander and American Indian or Alaskan Natives.

Research suggests that a large-scale initiative at the policy or organization level is most helpful in encouraging race and ethnicity data collection throughout the health ecosystem. [2]

Findings Within Data Source

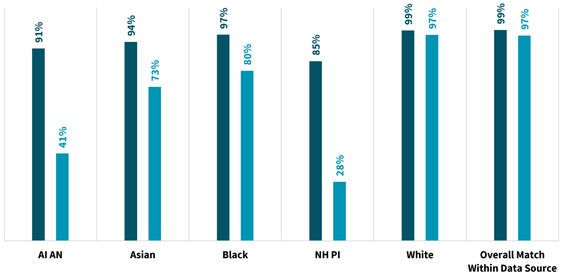
Legend for both graphs: APCD, Hospital

Demographic Breakdown by MHDO Data Source Among Individuals in Both Data Sets



Individuals can fall into one or more racial categories; as a result, values will not add up to 100%

Consistency of Race Classification Within Each MHDO Data Source Among Individuals With Reported Racial Group at Least Once



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References: 1. Office of Management and Budget (OMB). (1997) "Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity."
2. MHDO (2022). "Best Methods and Definitions to Use in Collecting Data to Better Understand Racial and Ethnic Disparities in the Provision of Health" Care in Maine

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