



MHDO Maine Health
Data Organization
Information | Insight | Improvement

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Ambassador Maulian Dana and Representative Rachel Talbot Ross, Co-Chairs,
and Whitney Parrish, Interim Executive Director, Permanent Commission on the Status of Racial, Indigenous and Maine Tribal Populations
Ian Yaffe, Director, Office of Population Health Equity, DHHS
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FROM: Karynlee Harrington, Executive Director, Maine Health Data Organization

RE: Public Law 2021, Chapter 34

Public Law 2021, Chapter 34. *Resolve, Directing the Maine Health Data Organization to Determine the Best Methods and Definitions to Use in Collecting Data to Better Understand Racial and Ethnic Disparities in the Provision of Health Care in Maine*, requires the Maine Health Data Organization (MHDO) to develop a report on the best methods and definitions to use in collecting data to better understand racial and ethnic disparities in the provision of health care in Maine.

Attached is a copy of our report. Please don't hesitate to contact me directly with any questions.



PRINTED ON RECYCLED PAPER

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Executive Summary

Summary

Public Law 2021, Chapter 34, Resolve, *Directs the Maine Health Data Organization (MHDO) To Determine the Best Methods and Definitions to Use in Collecting Data to Better Understand Racial and Ethnic Disparities in the Provision of Health Care in Maine*. The MHDO is required to submit its report, including suggested legislation based on its evaluation, by January 1, 2022 to the Joint Standing Committee on Health Coverage, Insurance and Financial Services.

Under contract with MHDO, Human Services Research Institute (HSRI) provided MHDO technical support in the preparation of this report.

Best Methods and Definitions

Based on our literature review, the following is a list of best practices for collecting race and ethnicity data.

1. Include, as a minimum, these six categories for collecting and identifying racial groups (based on Health and Human Services /Office of Management and Budget Standard¹):
 - American Indian/Alaska Native
 - Asian
 - Black or African American
 - Native Hawaiian or Other Pacific Islander
 - White
 - Other Race
2. Include, as a minimum, these two categories for collecting and identifying ethnicity (based on Health and Human Services /Office of Management and Budget Standard¹):
 - Hispanic or Latino
 - Not Hispanic or Latino
3. Provide options for collecting information on more than one race.
4. Collect information at a more granular level than the broad categories listed above (based on Center for Disease Control/HL7 Standard²), being mindful to not overly define the categories so patients and caregivers still feel comfortable self-reporting.
5. Obtain self-reported race and ethnicity information from the patient or patient's caregiver.
6. Hospital systems should have standardized processes for data collection and data storage, and for providing educational information to patients about the collection of this information.

Introduction and Background

Introduction

In 2019, the Maine Legislature created the Permanent Commission on the Status of Racial, Indigenous and Maine Tribal Populations. The 12-member Commission is charged with studying the status of historically disadvantaged populations, conducting public hearings and outreach to learn more about the challenges and needs of Maine’s racial and ethnic minorities and tribes, and making recommendations to the governor and Legislature to advance racial justice. In September 2020, the Permanent Commission published this report, [Recommendations to the Legislature](#).

One of the recommendations from this report called for the allocation of resources to address health disparities. For proposed and future legislation, it is important to ensure accurate data collection on the diverse racial and ethnic backgrounds of Maine citizens. It is difficult to assess the healthcare environment and success of related legislation without having this key piece of information. The best method to meet this goal is to have standardized practices within the healthcare system surrounding the collection of self-reported race and ethnicity data.^{3,4} Part of the methodology for the 2020 U.S. Census involved collecting detailed data by asking citizens to specify their specific racial and ethnic background.⁵

Obtaining detailed race and ethnicity data allows the opportunity to gather insight into the healthcare-related experiences for the subpopulations within a community. This insight can drive program and policy initiatives focused on addressing health disparities.

For the purposes of this report, race is defined as a self-identified representation of ancestral origin or cultural groups, while ethnicity is defined as whether or not a person identifies as Hispanic or Latino.^{6,7} This definition is consistent with the U.S. Census identification and collection of race and ethnicity information.^{1,5}

Background

Public Law 2021, Chapter 34, *Resolve, Directing the Maine Health Data Organization To Determine the Best Methods and Definitions To Use in Collecting Data To Better Understand Racial and Ethnic Disparities in the Provision of Health Care in Maine*, requires the Maine Health Data Organization (MHDO) to submit a report to the Joint Standing Committee on Health Coverage, Insurance and Financial Services by January 1, 2022, on the best methods and definitions to use in collecting data to assist in analyzing the origins of racial and ethnic disparities in health care in the State.

MHDO’s Approach

To determine the best methods for the collection of race and ethnicity data, MHDO established the following study goals:

- Understand how PL 2021, Ch. 34 relates to the data recommendations put forth in September 2020 by the Permanent Commission

- Explore and document current data collection methods and definitions, which includes the identification and review of existing national standards regarding the collection of race and ethnicity data
- Document data collection methods and definitions currently in use for collecting hospital encounter and health care claims data in Maine, as defined in MHDO’s data collection Rules Chapter 241 and 243 specific to race and ethnicity fields
- Evaluate patterns and inconsistencies across facilities and payers in analysis of race and ethnicity information
- Understand how race and ethnicity data are currently collected and entered into systems at the point of care or insurance, including the current barriers to consistently collecting information
- Identify the gaps in current health data collection efforts
- Convene a MHDO Stakeholder Group to review current practices and inform recommended changes

Maine Health Data Organization (MHDO)

MHDO was created by the Legislature in 1995 as an independent executive agency that operates under the supervision of a multi-stakeholder Board of Directors. The Governor appoints members of the Board, which includes representation from payers, hospitals, providers, consumers, employers, and government.

Purpose

MHDO’s mandate, as described in Title 22, Chapter 1683, is to create and maintain a useful, objective, reliable, and comprehensive health information data warehouse that is used to improve the health of Maine citizens and to promote transparency of the cost and quality of health care in the State of Maine, in collaboration with the Maine Quality Forum.

MHDO is responsible for the collection, storage, management, and release of healthcare data, which includes claims data, prescription drug pricing data, hospital inpatient and outpatient encounter data, hospital quality data, and hospital financial and organizational data. MHDO maintains over 1 billion healthcare records and that number continues to grow every month as new data are submitted. For years, MHDO’s data have been an important data source for a broad set of authorized data users in their analysis of health care costs, utilization, and outcomes in the state of Maine. The identification of the organizations and the ways in which they request to use MHDO’s data is available on the [MHDO website](#).

Race and Ethnicity Data Currently Collected by MHDO

Race and ethnicity information is submitted to MHDO through one of the following two data sources:

1. 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 as defined in 90- 590 CMR

Chapter 241, *Uniform Reporting System for Hospital Inpatient Data Sets and Hospital Outpatient Data Sets*.

2. All-Payer Claims Data (APCD) – includes Medical, pharmacy and dental claims data from Commercial, MaineCare, and Medicare as defined in 90- 590 CMR Chapter 243, *Uniform Reporting System for Health Care Claims Data Sets*.

More details on how these data are currently being collected is found in Appendix B: Data Elements.

Highlights of Race and Ethnicity Data Collected by MHDO

MHDO Hospital Encounter Data

- Overall, 87% of hospital encounter records from 2017-2020 had data available for patient's race and 84% of them for patient's ethnicity (*Table 1*).
- Inpatient hospital encounters were more likely than outpatient hospital encounters to have race and ethnicity information present on the record, with 95% or more of hospital encounters having valid values in any given year between 2017-2020.
- *Table 3* displays the share of each race and ethnicity category available in the hospital encounter data, based on a count of individuals with the respective category on at least one encounter record.

MHDO All-Payer Claims Data (APCD)

- In the APCD medical eligibility data submissions for January-June 2021, less than 50% of records included race or ethnicity information (*Table 2*).
- Race information was more likely to be present for MaineCare (93%) than for Commercial payers (6%) (*Table 2*).
- *Table 4* displays the share of each race and ethnicity category available in the APCD, based on a count of individuals with the respective category on at least one of the medical eligibility records.

Table 1: MHDO Hospital Data: Race and Ethnicity Field Use Among Hospital Encounters, 2017-2020

	2017	2018	2019	2020	2017-2020
Overall					
Race Specified	77.4%	75.5%	96.9%	97.4%	86.6%
Ethnicity Specified	75.6%	73.0%	95.1%	94.8%	84.4%
Total Number of Encounters	7,832,680	7,789,021	7,918,481	7,080,566	30,620,748
Inpatient					
Race Specified	97.4%	97.8%	99.1%	99.0%	98.3%
Ethnicity Specified	95.1%	94.9%	95.6%	95.6%	95.6%
Total Number of Encounters	145,320	141,410	141,523	124,552	552,805
Outpatient					
Race Specified	77.0%	75.0%	96.9%	97.4%	86.3%
Ethnicity Specified	75.2%	72.6%	95.1%	94.7%	84.2%
Total Number of Encounters	7,687,360	7,647,611	7,776,958	6,956,014	30,067,943

Data Source: MHDO's Hospital Encounter Data

Table 2: Race and Ethnicity Field Use Among APCD Medical Eligibility Records, January – June, 2021

	Commercial	Medicaid (MaineCare)	Overall
Race Specified	5.6%	93.2%	39.5%
Ethnicity Specified	2.1%	1.6%	4.0%
Total Number of Records	6,103,671	4,111,614	11,203,204

Data Source: MHDO's Claims Database

Table 3: MHDO's Race and Ethnicity Data for Hospital Encounters, 2020

	Inpatient		Outpatient		Overall	
	Number	Percent	Number	Percent	Number	Percent
RACE						
American Indian/ Alaskan Native	518	0.6%	4,764	0.5%	4,832	0.5%
Asian	591	0.7%	8,873	0.9%	8,939	0.9%
Black	1,952	2.2%	20,605	2.0%	20,850	2.0%
Native Hawaiian/Pacific Islander	61	0.1%	784	0.1%	790	0.1%
White	85,366	95.5%	998,577	95.8%	1,004,499	95.7%
Other Race	1,058	1.2%	16,329	1.6%	16,577	1.6%
Total Individuals	89,385		1,042,876		1,049,173	
ETHNICITY						
Hispanic	1,016	1.2%	14,917	1.5%	15,068	1.5%
Non-Hispanic	85,206	98.9%	1,008,679	98.8%	1,014,186	98.8%
Total Individuals	86,170		1,020,906		1,026,491	

Data Source: MHDO's Hospital Encounter Data

Table 4: MHDO's Race and Ethnicity Data for APCD Medical Eligibility Records, January – June, 2021

	Commercial		Medicaid (MaineCare)		Overall	
	Number	Percent	Number	Percent	Number	Percent
RACE						
American Indian/ Alaskan Native	351	0.5%	6,505	1.7%	6,914	1.5%
Asian	587	0.9%	4,904	1.3%	5,518	1.2%
Black	445	0.7%	19,435	5.1%	19,956	4.2%
Native Hawaiian/Pacific Islander	93	0.1%	691	0.2%	790	0.2%
White	64,272	98.5%	341,058	89.8%	432,584	91.8%
Other Race	329	0.5%	18,729	4.9%	19,371	4.1%
Total Individuals	65,271		379,751		471,377	
ETHNICITY						
Hispanic	391	1.6%	8,037 ¹	N/A	8,451	N/A
Non-Hispanic	24,431	98.4%	N/A	N/A	N/A	N/A
Total Individuals	24,822		8,037		N/A	

Data Source: MHDO's Claims Database

¹ MaineCare data only include the value Y in the Hispanic indicator, as such we have not computed percentages. We are unsure if the blank values are missing or represent non-Hispanic.

Evaluation, Design and Methods

Literature Review

Standardized data collection is essential for understanding health disparities and tracking progress in reducing them.⁸ Collecting race and ethnicity data is a necessary component to understanding the relationship between health, healthcare systems and the populations they serve, as well as other factors associated with health care disparities.⁶

While data collection has come a long way in the past 20 years, the data does not always flow in a cohesive and standardized way between collecting entities.³ To fully understand how to address the collection of race and ethnicity data in a standard way, it is important to take stock of the current processes and requirements surrounding data collection and information exchanges across the health care ecosystem, including hospitals; health centers; practices; health plans; and local, state, and federal agencies.

The goal of interoperability in health care information provides the foundation for requiring the implementation of data collection standards in electronic health record (EHR) technology. As such, the process of certification to EHR standards has created opportunities to standardize the collection of race and ethnicity data. In 2015, the Office of the National Coordinator for Health Information Technology (ONC), Department of Health and Human Services (HHS) included in its certification criteria that certain health care facilities covered under the Medicare and Medicaid programs (receiving funding from) should adhere to these standards.⁹ The Office of the National Coordinator for Health Information Technology publishes the US Core Data for Interoperability (US CDI).¹⁰ Health Information Exchange (HIE) uses this as a guide for the collection, standardization and, aggregation of data (including race/ethnicity data) from EHRs.

The 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.^{11,12,13} For example, one study looking at the collection of race and ethnicity data across payer types (Medicaid, Medicare, and Commercial) found that payers with reporting requirements (Medicaid and Medicare) are more likely to have complete data.¹³ Another study looking at health plans found that those with an organization-level initiative that encompassed all plans and departments had more complete data compared to others.¹¹ The Asian and Pacific Islander American Health Forum recently released a report outlining legislative action and systems level changes in the standardization of collection and reporting of race and ethnicity data as a foundational necessity in understanding and addressing health disparities.¹⁴

There are other aspects that play a role in the quality of data and collection practices for race and ethnicity data, such as inconsistencies in how the data are collected. For example, some systems collect patient-level self-reported racial and ethnicity information upon admission or intake, while others rely on indirect methods such as having staff report the assumed racial or ethnic identity or using geocoding software to infer race and ethnicity based on the preponderance of a racial or ethnic group in the geographic area where the patient resides.^{4,11}

The response options that are used for the identification of race and ethnic groups are also inconsistent.^{11,12,15} For example, some allow the selection of multiple race or ethnic groups while

others only allow the patient or member to select one.^{4,11,16} Staff and patient training are essential elements in facilitating data collection. For example, some barriers mentioned in the literature included staff discomfort with collecting this information and patient discomfort in disclosing this information.^{12,16,16}

Review of Existing Methodologies

Current Federal Standards

In 1977, the Office of Management and Budget (OMB) established a minimum standard for the collection of race and ethnicity information from respondents of federal surveys. These minimum standards are required to be included by HHS for all population surveys that are supported by the organization.¹⁷ The minimum standard was revised in 1997 and is used in its revised form to this day.

The OMB minimum standard categories are:

- **Race** – the OMB standard indicates that the respondent can select multiple values, if applicable, **from six categories**:
 - American Indian or Alaska Native
 - Asian
 - Black or African American
 - Native Hawaiian or Other Pacific Islander
 - White
 - Other Race

- **Ethnicity**:
 - Hispanic or Latino
 - Not Hispanic or Latino

Aside from the standard categories of race and ethnicity, the OMB standard also involves the collection of these elements through self-identification rather than through observation of the interviewer, the latter being more prone to introducing bias and inaccuracies.

The U.S. Centers for Disease Control and Prevention (CDC) has established a code set for use in coding race and ethnicity data. This code set is based on current federal standards for classifying data on race and ethnicity, specifically the minimum standard race and ethnicity categories defined by the OMB and a more detailed set of over 900 race and ethnicity categories maintained by the U.S. Census Bureau (USCB). The main purpose of the code set is to facilitate use of federal standards for classifying data on race and ethnicity when these data are exchanged, stored, retrieved, or analyzed in electronic form.

The code set can also be applied to paper-based record systems to the extent that these systems are used to collect, maintain, and report data on race and ethnicity in accordance with current federal standards. The code set includes the OMB minimum list of categories as the overarching categories and a more detailed set of race and ethnicity subcategories used by the USCB. In May 2021, the Office of the National Coordinator for Health Information Technology made the use of

this code set required for EHR certification purposes, with the goal of assisting in health equity efforts.¹⁸

The overarching categories used by the USCB adhere to the basic classification framework provided by the OMB standards, with the notable exception of the exclusion of Other Race, used to collect and tabulate decennial census data. The USCB collects more detailed race and ethnicity data by asking respondents to self-identify their race and ethnicity in a series of categorical questions and free text data fields.² The USCB’s summarization and categorization of these responses provide a detailed set of race and ethnicity concepts, grouped in accordance with the OMB standards. Below is an excerpt from the CDC standard that illustrate the high-level Race Category R1 American Indian or Alaska Native, and then shows examples of the more detailed categories underneath.

Table 5 – Race Concepts and Codes

Unique Identifier	Hierarchical Code	Concept
1000-9	R	Race
1002-5	R1	American Indian or Alaska Native
1004-1	R1.01	American Indian
1006-6	R1.01.001	Abenaki
1008-2	R1.01.002	Algonquian

Comparison of Data Elements

Standards and Data Elements

The following tables illustrates the HHS OMB Standards on the left and examples from the CDC Race and Ethnicity Code Set that roll up into the OMB Standard.

² The detailed concepts in the Race and Ethnicity tables are based on the USCB’s summarization and categorization of responses to the March 1998 dress rehearsal for the year 2000 decennial census.

Race

HHS OMB Standards		CDC Race Code Set
American Indian/Alaskan Native	↕	American Indian Abenaki Maliseet Micmac Passamaquoddy Penobscot
Asian	↕	Cambodian Chinese Korean Filipino Asian Indian Singaporean
Black or African American	↕	African American African Nigerian Haitian Jamaican Trinidadian
Native Hawaiian or Other Pacific Islander	↕	Polynesian Samoan Tahitian Guamanian Yapese Fijian
White	↕	White European Egyptian Iranian Polish Italian
Other Race		Other Race

Ethnicity

HHS OMB Standards		CDC Ethnicity Code Set
Hispanic or Latino	↕	Spaniard Mexican Costa Rican Colombian Puerto Rican Cuban
Non-Hispanic or Latino	↕	Non-Hispanic or Latino

Current MHDO Data Submission Standards

For the MHDO data, both the Hospital Encounter and APCD data submission requirements use the HHS OMB standards, but only the APCD allows for the submission of multiple options for each category and the more detailed options in the CDC standard. The differences are summarized below, with details of each submission standard available in Appendix B.

MHDO Hospital Encounter Data	MHDO APCD (Claims Data)
Uses HHS OMB Standards	Uses HHS OMB Standards
One Option for Race	Uses CDC/HL7 Standards
One Option for Ethnicity	Three Options for Race Using CDC/HL7 Standards
	A Hispanic Indicator
	Three Options for Ethnicity using CDC/HL7 Standards

Best Practices

Collecting Race and Ethnicity Data

Based on our review of the literature, the following are best practices for collecting race and ethnicity data:

1. Include, as a minimum, six categories for collecting and identifying racial groups (based on HHS/OMB Standard):
 - American Indian/Alaska Native
 - Asian
 - Black or African American
 - Native Hawaiian or Other Pacific Islander
 - White
 - Other Race
2. Include, as a minimum, two categories for collecting and identifying ethnicity (based on HHS/OMB Standard):
 - Hispanic or Latino
 - Not Hispanic or Latino
3. Provide options for collecting information on more than one race.

4. Collect information at a more granular level than the broad categories listed above (based on CDC/HL7 Standard), being mindful to not overly define the categories so patients and caregivers still feel comfortable self-reporting.
5. Obtain self-reported race and ethnicity information directly from the patient or patient's caregiver.
6. Hospital systems should have standardized processes for data collection and data storage, and for providing educational information to patients about the collection of this information.

Sample Form

Based on the Best Practices described above, MHDO drafted a sample data intake form. As seen in Image 1, the HHS/OMB standards were incorporated as high-level categories for race and ethnicity questions, with more detailed options provided underneath each category. The detailed options were taken from the CDC/HL7 Standard, as available, and selected based on information specific to the populations in Maine. A question on language was also added, based on the American Community Survey (ACS) standard.

Image 1. Sample Data Intake Form

Race

What is your Race and Tribal Affiliation/Origin?
(One or more categories may be selected.)

- American Indian/Alaskan Native
(Please include your tribal affiliation(s))
 - Abenaki
 - Maliseet
 - Micmac
 - Passamaquoddy
 - Penobscot
 - Other: _____
- Asian
(Please mark or fill in more specific racial categories)
 - Asian Indian
 - Chinese
 - Korean
 - Vietnamese
 - Other: _____
- Black or African American
(Please mark or fill in more specific racial categories)
 - African American
 - Congolese**
 - Haitian
 - Rwandan**
 - Somali**
 - Other: _____
- Native Hawaiian or Other Pacific Islander
(Please mark or fill in more specific racial categories)
 - Guamanian
 - Native Hawaiian
 - Polynesian
 - Samoan
 - Other: _____
- White
(Please mark or fill in more specific racial categories)
 - Egyptian
 - English
 - Iranian
 - Italian
 - Other: _____
- Some Other Race: _____
- Choose not to Answer

Ethnicity

Are you Hispanic, Latino/a, or Spanish origin? (One or more categories may be selected.)

- No, not of Hispanic, Latino/a, or Spanish origin
- Yes, Mexican, Mexican American, Chicano/a
- Yes, Puerto Rican
- Yes, Cuban
- Yes, Another Hispanic, Latino/a or Spanish origin: _____

Language

How well do you speak English? (5 years old or older)

- Very well
- Well
- Not well
- Not at all

Note: **Bold** indicates category not part of current standard.

Convening MHDO's Stakeholder Group

A broad representation of stakeholders, including those who testified in support of LD 274, were invited to participate in MHDO's LD 274 Stakeholder Group meeting with the primary goal of seeking feedback from individuals on the findings to date; and to assist the MHDO in developing its report and recommendations (see Appendix D for a complete listing).

At the first meeting of the Stakeholder Group, MHDO detailed the race and ethnicity data that it collects from the hospital encounter and all-payer claims data and described the standards that MHDO relies on in the collection of these data. The second part of the meeting was to review the sample data collection form that MHDO developed.

Unfortunately, because there were key stakeholders that did not attend the meeting, the group was not comfortable providing feedback on the sample data collection form. At this point in the process, it became clear that MHDO is not the entity that has the relationships with these stakeholders; and that a body like the Permanent Commission or the Office of Population Health Equity are better positioned to continue the work of determining what should be included in a standardized data collection form specific to race and ethnicity. MHDO is prepared to help support these conversations; and it is MHDO's hope that this report provides a framework for continued conversations with a broader group of stakeholders in 2022.

Future Considerations and Opportunities

The following is a list of opportunities and actions that MHDO will continue to pursue because of producing this report and is based on feedback from our data user community:

1) Update MHDO's Data Release Rule

In December 2021, MHDO's Board of Directors provisionally adopted changes to MHDO's Rule [Chapter 120, Release of Data to the Public](#), to allow for broader access to the race and ethnicity data collected by MHDO. This is a major substantive rule and will require the Legislature approve the proposed changes when presented for consideration in 2022.

2) Expand the Number of Race and Ethnicity Data Elements in MHDO's Hospital Encounter Data

In order to align with the recommended standard, update MHDO's [Rule Chapter 241: Uniform Reporting System for Hospital Inpatient Data Sets and Hospital Outpatient Data Sets](#), by expanding the number of available fields for Race and Ethnicity information. This update will then align with the standard in MHDO's [Rule Chapter 243, Uniform Reporting System for Health Care Claims Data Sets](#) Consider

3) Add Primary Language as a Standard Data Element in MHDO's Hospital Encounter Data Submissions

The recommended Primary Language question to meet the minimum standard is based on the American Community Survey (ACS). Disparities have been associated with English language proficiency rather than specific language spoken.¹⁶ The standard for primary language is a measure of English proficiency and the recommended question is based on that used on the ACS.

4) Explore Feasibility of Data Linkages

Continue to explore the feasibility of linkages between the MHDO hospital encounter data, claims data and additional data sources, for the purpose of improving the comprehensiveness of the data.

5) Display Race and Ethnicity Statistics on MHDO's Website

Add aggregate statistics regarding the composition of race and ethnicity data that MHDO collects on MHDO's website.

6) Monitor Federal Standards for Updates

Continue to monitor Federal standards for updates to recommendations as they evolve.

7) Work to Identify Additional Data Elements to Address Health Equity

Leverage feedback from MHDO's data users to identify additional fields to be added to MHDO's data submission requirements to address health equity.

8) Collaborate with Other State Entities to Align Data Sources

Work with other State Entities to align the standard collection and use of race and ethnicity data. Employ a multi-phase strategic set of legislative and regulatory changes, and policy guidance and actions to guide the race and ethnicity data collection and reporting in the state.¹⁴

Appendices

Appendix A: Glossary of Terms

ACRONYM	DEFINITION
APCD	All-Payer Claims Database
CDC	Center for Disease Control and Prevention
ERISA	Employee Retirement Income Security Act
FQHC	Federally Qualified Health Center
HHS	U.S. Department of Health and Human Services
HIPPA	Health Insurance Portability and Accountability Act
HL7	Health Level Seven
HSRI	Human Services Research Institute
MHDO	Maine Health Data Organization
MQF	Maine Quality Forum
OMB	Office of Management and Budget
USCB	U.S. Census Bureau

Appendix B: Data Elements

Maine Hospital Encounter Data Elements

Chapter 241 submission layout for the Maine Hospital Encounter Data includes 2 fields, one for race information and the second for ethnicity information, for each data stream (inpatient and outpatient). The Chapter 241 field specifications are shown in table 5 below.

Table 5: Hospital Encounter Data Elements

Data Element #	Data Element	Implementation Date for New Data Elements	Type	Length	Description/Codes/Sources
IP2017/ OP2016	Race	March 1, 2007	T	1	1 = American Indian or Alaska Native 2 = Asian 3 = Black or African American 4 = Native Hawaiian or Other Pacific Islander 5 = White 6 = Other Race 7 = Patient Elected not to Answer 8 = Unknown
IP2018/ OP2017	Ethnicity	March 1, 2007	T	1	1 = Hispanic or Latino 2 = Non-Hispanic or Non-Latino 8 = Unknown

Maine APCD Data Elements

Chapter 243 submission layout for Maine APCD data includes 7 fields to submit race and ethnicity information. The Chapter 243 specifications for these fields are shown in table 6 below.

Table 6: APCD Data Elements

Data Element #	Data Element Name(s)	Date Effective	Type	Maximum Length	Description/Codes/Sources
ME021-23	Race 1-3	1/1/2021	Text	2	Report the Member-identified race. The code value "UN" (Unknown/not specified), should be used ONLY when Member answers unknown, or refuses to answer. Report only collected data. If not available, leave blank. For quick reference, the two-character subset of the CDC race list is: R1 American Indian/Alaska Native R2 Asian R3 Black/African American R4 Native Hawaiian or Other Pacific Islander R5 White R9 Other Race UN Unknown/Not Specified
ME024	Hispanic Indicator	1/1/2021	Text	1	Report the value that defines the element. The code value "U" for unknown, should be used ONLY when member answers unknown, or refuses to answer. Report only collected data. If not available, leave blank. Y Member is Hispanic/Latino/Spanish N Member is not Hispanic/Latino/Spanish U Unknown/not specified.
ME025-27	Ethnicity 1-3	1/1/2021	Text	6	Report the Member-identified ethnicity from the External Code Source that best describes the information obtained from the Member / Subscriber. The value "UNKNOW" should be used ONLY when the Member answers unknown or refuses to answer. Report only collected data. If not available, leave blank. Refer to HL7/CDC Race and Ethnicity Code Set

Appendix C: Additional Analysis

Variation Across Time and Between Facilities

For individuals for whom race, and ethnicity information provided more than once, patterns of consistency were examined across individual’s records to better understand the degree to which facilities (i.e., hospital submitters) may provide or obtain consistent information at different data collection points. To better capture this type of variation, the hospital encounter data was used, due to the availability of race and ethnicity information on a high proportion of records across time. Data was assessed using the enhanced MHDO-assigned Person ID and encounter records from 2017 to 2020.

First, a baseline race and ethnicity value within each facility was determined at the Person ID level based on the three most recent data points for that individual. All available records for the respective individual were compared against this baseline both within records from that facility and across records from all other facilities where the individual received services, where applicable, and the total proportion of matches was calculated.

Table 5 provides information on the consistency of race and ethnicity data for an individual across time, within and between hospital submitters. Based on this assessment, information within facilities appears to be relatively consistent, and less consistency is observed across facilities, particularly for patients associated with the American Indian/Alaskan Native racial group, Native Hawaiian or Other Pacific Islander racial group, and Hispanic or Latino ethnicity group. The most consistency was found among White residents in Maine.

Table 5: Consistency of Race and Ethnicity Reporting Within and Between Hospital Submitters, 2017-2020

	Total Number of Persons	Percent Matched Within Facilities	Percent Matched Between Facilities
Race	1,262,337	99.80%	98.23%
American Indian or Alaska Native	4,963	95.57%	57.21%
Asian	9,822	97.54%	71.26%
Black or African American	22,860	98.35%	82.66%
Native Hawaiian or Other Pacific Islander	826	90.98%	39.66%
White	1,202,409	99.91%	98.98%
Other Race	16,642	93.63%	47.63%
Ethnicity	1,242,992	93.56%	99.32%
Hispanic or Latino	15,009	88.04%	54.54%
Non-Hispanic or Non-Latino	1,227,983	93.61%	99.65%

DATA SOURCE: MHDO’S HOSPITAL ENCOUNTER DATA.

Appendix D: Invited Stakeholder Group

A broad representation of stakeholders, including those who testified in support of LD 274, were invited to participate in the MHDO LD 274 Stakeholder Group Meeting by providing input to the MHDO on the development of the report due on January 1, 2022, to the Joint Standing Committee on Health Coverage, Insurance, and Financial Services.

Organizations Invited to Participate in the Stakeholder Group

- ACLU of Maine
- Consumers for Affordable Health Care
- Cross Cultural Community Services
- HealthInfoNet
- Immigrant Resource Center of Maine
- Maine Access Immigrant Network
- Maine Association of Health Plans
- Maine Center for Disease Control and Prevention's Office of Population Health Equity
- Maine Center of Economic Policy
- Maine Department of Health and Human Services
- Maine Health Access Foundation
- Maine Hospital Association
- Maine Immigrants' Rights Coalition
- Maine Primary Care Association
- Maine Public Health Association
- New Mainers Public Health Initiative
- Partnership for Children's Oral Health
- Portland Public Health Minority Health
- UMaine Center for Community Inclusion and Disability Studies
- Wabanaki Public Health

Collaborating Subject Matter Experts

The following organization provided support and subject matter expertise in the development of this report:

- University of Southern Maine

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