Care Transformation Collaborative of Rhode Island (CTC-RI) Demographic Data Collection Pilot Environment Scan: Current and Anticipated Standards Requirements Summary Report

Contents

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Background

The Rhode Island Department of Health (RIDOH) has been granted the Center for Disease Control and Prevention (CDC) National Initiative to Address COVID-19 Health Disparities among Populations at High-Risk and Underserved, including Racial and Ethnic Minority Populations and Rural Communities Award. As part of this grant, CDC has identified improving health outcomes with priority given to increasing and improving demographic data collection and reporting. Important activities associated with this strategy include:

- Building on plans for collecting and reporting timely, complete, representative, and relevant data;
- Educating providers, community partners and programs on the importance of data and how to collect it;
- Disseminating health equity-related data and related materials tailored to be culturally and linguistically responsive;
- Providing resources for collecting, analyzing, reporting, and disseminating health equity-related data and for data infrastructure and workforce.

Improving demographic data collection is a foundational activity for promoting health equity and addressing COVID-19 health disparities. COVID-19 has disproportionally affected populations who are medically underserved including community members who are Black, Indigenous, and People of Color (BIPOC) and people living in rural communities. The intent of improved demographic data collection is to assist providers who work with priority populations (including BIPOC communities, groups that are more effectively served in a language other than English, veterans, people who are unhoused or housing insecure, the LGBTQ+ community, people living with disability or in rural communities) apply this information to understand and improve gaps in care.

Given the long-understood impact of healthcare disparities, the importance of complete and accurate collection of race and ethnicity data is unquestionable. Equally important in a small state such as Rhode Island is the ability to meaningfully aggregate data across care settings, which demands an understanding of existing and proposed standards for data collection, as well as consideration for aligning stakeholders across the state on one standard among multiple potential options, particularly when participants are answerable to multiple regulatory or payer organizations.

The current race and ethnicity standards were reviewed for specified federal, state, and certification program requirements and assembled into a Reporting Standards Matrix. The matrix includes reporting standards for the Centers for Medicare & Medicaid Services (CMS), US Office of Management & Budget (OMB), Health & Human Services (HHS), Health Resources & Services Administration (HRSA), U.S. Census Bureau (Census), Substance Abuse and Mental Health Services Administration (SAMHSA), Rhode Island Department of Health (RIDOH), Executive Office of Health and Human Services (EOHHS) and the National Committee for Quality Assurance (NCQA). This portion of the environmental scan will inform the CTC Demographic Data Collection pilot project as they prepare to develop a webinar series to improve collection and reporting. It is important to factor in all applicable current standards and requirements to streamline the collection process and to ensure that all workflows and required systems changes are implemented to include any anticipated standards and/or requirements. This work may also inform the EOHHS as they work with Accountable Entities (AEs) to establish incentives to improve the complete and accurate collection of demographic data in support of reducing health disparities in the state.

Approach

The goal of this report is to review, assemble, and analyze the current and proposed requirements for the collection and reporting of demographic data (specifically focused on race and ethnicity) in healthcare delivery and payment settings for the purposes of: 1) developing improvement efforts, including a webinar training series for the primary care practices participating in the demographic data collection pilot project; and 2) considering policies to support the alignment on one standard for practices in the state. There are four components to this review: 1) Identification of the set of common data elements used in current demographic data collection; 2) Discussion on the most widely used standards; 3) Gaps in data collection within these standards; and 4) Recommendations and next steps.

The project team conducted a search of demographic data collection standards, with particular attention to race and ethnicity data. The focus was given to national, federal, and state organizations that have requirements and programs that most primary care practices utilize to meet regulations and for additional recognition and/or accreditation. The project team developed a matrix with key components from each source to identify consistent data that is collected. Refer to Appendix I for the *Race and Ethnicity Data Standards Matrix* that was developed to identify key demographic standards and components. Data analysis and comparison was completed on the matrix and additional research was completed on standards developed by the Office of Management and Budget in 1997 (1). Adrian Bishop, EOHHS Consultant, was consulted and his research and PowerPoint slides were included.

Key Findings

Current State Analysis

Reporting Standards Matrix
The planning team created a matrix comprised of national, federal, and local standards that are followed by most and available to primary care practices in Rhode Island. The Race and Ethnicity standards that were reviewed and included in this analysis are from the following organizations:

- Federal: Office of Management and Budget (OMB), Health and Human Services (HHS), Centers for Medicare & Medicaid Services (CMS) Medicare (Medicare Advantage), CMS Medicaid, Health Resources and Services Administration Uniform Data System (HRSA UDS), 2020 Census

- State of Rhode Island: Medicaid (both Federally Qualified Health Center (FQHC) and Non FQHC) incorporated in the Accountable Entity program.

- Behavioral Health: Substance Abuse and Mental Health Services Administration (SAMHSA) and Behavioral Health On-Line Database (BHOLD)

- <u>National</u>: National Committee for Quality Assurance Healthcare Effectiveness Data and Information Set (NCQA HEDIS), CMS Electronic Clinical Quality Measures (CMS ECQM), NCQA Patient Centered Medical Home Recognition Program (NCQA PCMH) and NCQA Health Equity (NCQ HE) Accreditation

Each organization's program has its own requirements for the categories of race and ethnicity that are displayed in the matrix (Appendix I).

Current Standards / Requirements

<u>OMB</u>
The most widely used standards for Race and Ethnicity is led by the OMB and was the implementation of the 1997 Standards on Race and Ethnicity (1). These are referred to as the OMB minimum requirements and include 1 Ethnic category and 5 Race categories – (See below and Refer to Appendix II)

Office of Management and Budget (OMB) Standards

The Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity (OMB Statistical Policy Directive No. 15) define minimum standards for collecting and presenting data on race and ethnicity for all Federal reporting.

The race and ethnic categories are presented as separate questions, and individuals can select multiple racial categories. The OMB standards have one category for ethnicity—Hispanic or Latino—and five minimum categories for data on race.

- **Ethnic Categories**
  - Hispanic or Latino

- **Racial Categories**
  - American Indian or Alaska Native
  - Asian
  - Black or African American
  - Native Hawaiian or Other Pacific Islander
  - White

As part of the OMB standard, self-identification is the preferred method of obtaining a patient's race and ethnicity. The recommendation was to ask ethnicity first and then race. The 1997 OMB minimum categories for Race are: American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Other Pacific Islander, and White and minimum categories for ethnicity are: Hispanic or Latino and Not Hispanic or Latino (3). The **Census, SAMHSA, BHOLD, NCQA, CMS eCQM** all follow the OMB 1997 standards and do not offer granular data choices. They all, except eCQMs however, offer the option of refusal to answer and allow for choosing more than one race (which is not part of the OMB 1997 standard). CMS eCQMs and Census offer "other race" to be selected. They all follow the OMB 1997 standards for ethnicity except the Census; they follow the HHS standards for ethnicity by allowing for the granular data collection for the Hispanic / Latino category.

RI Medicaid / RI Medicaid (FQHC)

Both FQHC and Non-FQHC practices with patients on Medicaid follow OMB 1997 standards as a base except, in addition, they permit the respondent the ability to refuse to reply and allow for more than one race choice. They also follow the OMB 1997 standard for ethnicity except they allow the ability for refusal to answer. Meeting these standards is a requirement of the Rhode Island Accountable Entity Program (AE). FQHCs in Rhode Island meet requirements identified by Medicaid and adhere to more recent changes outlined in the HRSA/UDS section below.

HRSA/UDS

In 2022 HRSA adopted an expanded version of the 1997 OMB requirements that were originally proposed in 2011 for UDS FQHC reporting. This expanded the 1997 requirements from one to three ethnicity categories and from five to fourteen race categories. HRSA requires FQHCs to use the HHS standards for UDS reporting. HHS's data standards are based on the disaggregation of the OMB standard used in the American Community Survey (ACS) and the 2000 and 2010 Decennial Census (3). The ethnicity categories were expanded to Not of Hispanic, Latino/a, or Spanish Origin; Mexican, Mexican American, Chicano/a; Puerto Rican; Cuban; and Another Hispanic, Latino, or Spanish Origin. These were then rolled up to the Hispanic or Latino category of the 1997 OMB standard. HHS also did this for the Race with the expansion of the Asian and Native Hawaiian or Other Pacific Islander categories of the 1997 OMB Standard (4). (See below and Refer to Appendix III for the HHS Race and Ethnicity Stratification breakdown). In addition, CMS is planning to adopt these requirements for Medicare/Medicaid reporting. RI Medicaid will need to adjust to these requirements hence alignment between UDS and Medicaid and Medicare.

Ethnicity Data Standard	Categories
Are you Hispanic, Latino/a, or Spanish origin (One or more categories may be selected) a. ___No, not of Hispanic, Latino/a, or Spanish origin b. ___Yes, Mexican, Mexican American, Chicano/a c. ___Yes, Puerto Rican	These categories roll-up to the Hispanic or Latino category of the OMB standard

Race Data Standard	Categories
What is your race? (One or more categories may be selected) a. ___White b. ___Black or African American c. ___American Indian or Alaska Native	These categories are part of the current OMB standard
d. ___Asian Indian e. ___Chinese f. ___Filipino g. ___Japanese h. ___Korean i. ___Vietnamese j. ___Other Asian	These categories roll-up to the Asian category of the OMB standard
k. ___Native Hawaiian l. ___Guamanian or Chamorro m. ___Samoan n. ___Other Pacific Islander	These categories roll-up to the Native Hawaiian or Other Pacific Islander category of the OMB standard

The 2022 HHS data standards for race and ethnicity, as noted above, are based on the disaggregation of the OMB standard used in the American Community Survey (ACS) and the 2000 and 2010 Decennial Census. The data standard for ethnicity can be found in the diagram below and Appendix V. Race and ethnicity data collection applies to survey participants of all ages. (8)

Ethnicity Data Standard *Are you Hispanic, Latino/a, or Spanish Origin? (One or more categories may be selected)*

Categories	Notes
a. _____ No, not of Hispanic, Latino/a, or Spanish origin	
b. _____ Yes, Mexican, Mexican American, Chicano/a	
c. _____ Yes, Puerto Rican	These categories roll-up to the Hispanic or Latino category of the OMB standard
d. _____ Yes, Cuban	
e. _____ Yes, Another Hispanic, Latino/a or Spanish origin	

NCQA PCMH / NCQA HE / NCQA HEDIS

These programs follow the OMB 1997 standards except offer the ability to refuse answering and allow for more than one race choice. They also follow the OMB standard for ethnicity except allow for refusal to answer. HEDIS allows for the option of "Unknown" for ethnicity.

The NCQA standards, for both Patient Centered Medical Home and the Health Equity accreditation programs require data collection on patient demographics. The section labeled Competency B of the NCQA Patient Centered Medical Home standards are related to Patient Diversity. Patient Diversity is made up of A) Race, B) Ethnicity, C) Gender Identity, D) Sexual Orientation and (E) One other aspect of diversity. One other aspect of diversity, which may include, but is not limited to, religion, occupation, geographic residence, pronouns, disability status, veteran status. Neither age nor gender are acceptable as a fifth aspect of diversity (refer to Addendum VI). Note: these standards use the terminology "gender" but mean "sex assigned at birth".

The NCQA 2023 Health Equity program Standard 2 is entirely dedicated to the collection of demographic data and the protection of that data. Each category is broken down into an element within Standard 2 as follows (refer to Addendum VII):

- Element A: Systems for Individual-Level Data
- Element B: Collection of Data on Race/Ethnicity
- Element C: Collection of Data on Language
- Element D: Collection of Data on Gender Identity
- Element E: Collection of Data on Sexual Orientation
- Element F: Privacy Protection for Data
- Element G: Notification of Privacy Protections

The NCQA 2023 Health Equity program also includes Standard 6 which address Reducing Health Care Disparities and Standard 7 for the Delegation of Health Equity Activities. The target audience for both NCQA programs are primary care physician offices / organizations/health plans and require demographic data to be collected directly from the patient.

Common Demographic Data Elements Collected

The common data elements considered in this project were race, ethnicity, language, sex assigned at birth, gender identity, and sexual orientation, with the primary focus on race and ethnicity. As we learned from the literature review and key informant interviews for this project, data on race, ethnicity, preferred language, and sex assigned at birth are commonly collected, while practices, other than Federally Qualified Health Centers (FQHCs), across the state are in the early stages of collection of SOGI data. Note: when collecting SOGI data, there is difference with the use of sex and gender. Sex refers to a patient sex that is assigned at birth. Gender in most cases refers to gender identity which is how a patient identifies at the time the question is asked. HRSA has mandated that FQHCs collect and report SOGI data from all patients; however, about 20% of patients choose not to provide the data. NCQAs Patient Centered Medical Home accreditation program more recently required practices to collect SOGI data.

Most Widely Used Standards

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According to the Office of Minority Health (OMH), the 1997 OMB standard is used as a starting point for their race and ethnicity standards. They began with the OMB standards and utilized testing and survey data from OMB statistical agencies and programs to help inform their data collection standards and rational for selection (4). The OMH used the OMB standards for Race and Ethnicity and included Sex, Primary Language and Disability Status.

The National Center for Educational Statistics also follows the OMB and Department of Education Guidelines when defining race and ethnicity. Their purpose is to promote common language and uniformity when collecting and reporting on this data. (5)

The majority of the Federal, State, Behavioral Health, Quality Measures and NCQA all utilize the OMB 1997 standards. HHS, CMS Medicare and HRSA UDS expand on them and then reaggregate the data to roll back up to the OMB standards. This allows organizations to review the subpopulations in their communities and be able to assess the needs and support required to improve those populations.

Common Data Standards used for Race by the programs displayed within the reporting standards matrix are as follows:
- **American Indian or Alaska Native**
    - Note: SAMHSA expands their choice of Alaska Native to include Aleut and Eskimo
- **Asian**
    - Note: HSS, CMS Medicare and HRSA UDS allow for expanded choices that include Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, and Other Asian
- **Black or African American**
    - Note: BHOLD only offers Black as an option for this category
- **Native Hawaiian / Other Pacific Islander**
    - Note: HHS, CMS Medicare and HRSA UDS expand their choices to also include Guamanian or Chamorro; and Samoan. SAMHSA includes Asian as part of the Asian or Pacific Islander choice.
- **White**
- Race Declination
    - Offered by CMS Medicare, HRSA UDS, RI Medicaid (both Non FQHC and FQHC), NCQA HEDIS, PCMH and HE programs.
- Multiple Race Options
    - Those that allow more than one race choice: HRSA UDS, RI Medicaid (FQHC), NCQA PCMH and HE programs
    - Those that allow two or more race choices: RI Medicaid (Non-FQHC), SAMHSA, NCQA HEDIS

Note: there is no difference between those that allow "more than one" and "two or more". The language used refers to how the organization exactly states what is within their requirements.

Common Data Standards used for Ethnicity by all programs within the reporting standards matrix are as follows:
- **Hispanic / Latino**

- o Note: HHS, CMS Medicare, HRSA UDS, Census, and SAMHSA expand this category to include Mexican, Mexican American, Chicano/a, Puerto Rican, Cuban and Another Hispanic, Latino/a or Spanish Origin
  - o BHOLD only offers the choice of Hispanic
- **Not Hispanic or Latino**
  - o All organizations offer this choice except BHOLD - a yes or no response is prompted.
- Ethnicity Declination
  - o Offered by CMS Medicare, HRSA UDS, RI Medicaid (both Non FQHC and FQHC), NCQA HEDIS, PCMH and HE programs.
- Other Ethnicity Options
  - o Form Left Blank – offered by CMS Medicare only
  - o Unknown – offered by RI Medicaid (Non-FQHC), SAMHSA, NCQA HEDIS
  - o Not Collected – offered by SAMHSA only

All of these organizations use the OMBs 1997 standards for Race and Ethnicity as displayed in the Race and Ethnicity Data Matrix. Some organizations offer an expanded / granular breakdown of options for patients while the majority only offer the minimum standards. FQHC practices collect the minimum OMB standards while having to also meet HHS requirements. Refer to Appendix II for the 2011 HHS Race and Ethnicity Stratification that was adopted for FQHCs.

Data Collection Gaps

Given what we learned in the literature review for this project regarding respect for the patient as well as what we see as the limitations of the 1997 OMB standards for race and ethnicity, the most significant gap in the most commonly used standard is the inability of individuals to see themselves in the available choices. Being forced into a single choice for race presents a challenge, as does not seeing a choice which reflects one's identity as an option. For example, Rhode Island has a large population of people from Cape Verde, which has a majority (71%) Creole population, people of mixed African and European descent (6) and nearly 10% of the population of the village of Melville (straddling Portsmouth and Middletown) are of Middle Eastern descent (7). Additionally, given experience with systemic racism and discrimination, there is a small percentage (<10%) of patients who prefer not to provide information about race and ethnicity. Thus, critical gaps in data collection begin with the declination, unknown and Some Other Race response options available for race.

As noted above, in the *Current Standards* section, some organizations included in the *Race and Ethnicity Standards Data Matrix* provide options to collect patient data at a more granular level and allow for expanded choices, while others do not. For example, some organizations limit standard values for ethnicity to only two options, Hispanic / Latino or Not Hispanic / Latino. Fifty percent of the organizations included in our analysis allow two options while the other 50% offer additional choices of ethnicity. These choices include Mexican, Mexican American, Chicano/a, Puerto Rican, Cuban, and Another Hispanic or Latino/a or Spanish Origin. Fifty percent of the organizations also allow for a patient to decline to answer.

Twenty-one percent of the organizations on the *Race and Ethnicity Data Standards Matrix* allow for additional race choices for the Asian category (Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, Other Asian). Fourteen percent offer additional choices for Native Hawaiian / Other Pacific Islander. The breakdown is Native Hawaiian, Guamanian or Chamorro, Samoan, Other Pacific Islander. One of the Key Informants interviewed for this project, Dr. Stella Yi of New York University recommended adding "I do not identify as a more specific racial/ethnic group" and "Don't know/unsure" options. She also recommended changing "other" category to "not listed" and allowing for selection of multiple racial/ethnic categories. An additional suggestion was to alphabetize both aggregate and detailed race/ethnicity categories.

There are an extensive number of ethnicities that could be included in the Not Hispanic / Latino category. An accurate representation of a patient population cannot be determined if there are only the two choices of Hispanic / Latino or Not Hispanic / Latino. The new proposed OMB standards include additional expansion and will be discussed in a later section.
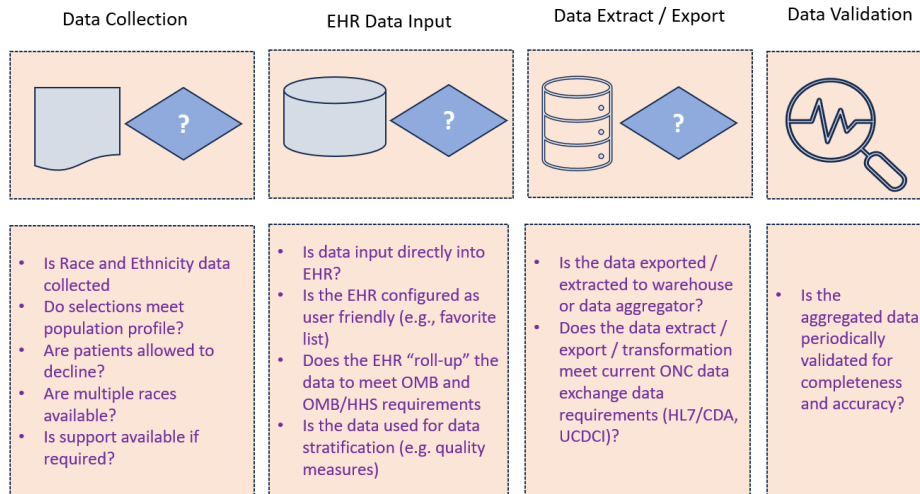
As noted in the Best Practice Literature Report and Key Informant interviews there are also some gaps in data reporting that could be addressed at the organizational level including staff education and accountability expectations for complete and accurate demographic data across all levels of the organization. Staff members may lack education on why the data is being collected, some do not have the time to collect the data and they are uncomfortable addressing patient questions about the demographic data. Staff training together with data collection measurement, reporting and quality improvement expectations for accuracy and completeness of data could assist with addressing current gaps in care.

There are 4 main areas that make up the demographic data collection through validation process. There could be gaps present in any or all of these areas.

- Data Collection: Collecting Race/Ethnicity, Preferred Language and SOGI data from all patients needs to be a foundational standard for primary care practices in order to accurately understand their patient panel and community. Data collection practices should allow patients to decline and have multiple race choices available (where more than one can be chosen). Staff should be equipped to provide patients with explanations about why data is being universally collected. Collection of SOGI data may be limited to adult patients.
- Data Input: Once the data is captured, it must be entered accurately into the EHR. The EHR must be configured to allow for data entry of all demographic data fields. It would be helpful for practices to create their own "favorites" or "frequently used", listing the patient population in mind. EHRs may need to be reconfigured or customized to include the more defined groups and the "roll-up" requirement from OMB/HHS. The disaggregated data could then be used for data stratification.
- Data Extract/Export: This data should be able to be easily exported or extracted. The EHR must be able to export the data in multiple formats to meet ONC data exchange requirements. These should include the capability to export into HL7/CDA formats and include UCDCI code requirements. EHRs should be able to also report for internal use to gain knowledge on their patient population to address health disparities.
- Data Validation: In all of the data collection, EHR data input, and data extract/export, practices must regularly review and validate the data for accuracy and completeness. (Refer to the diagram below summarizing the steps that can lead to potential gaps – Created and shared by Adrian Bishop)

Race and Ethnicity Data Nodes

Data Collection	EHR Data Input	Data Extract / Export	Data Validation

• Is Race and Ethnicity data collected • Do selections meet population profile? • Are patients allowed to decline? • Are multiple races available? • Is support available if required?	• Is data input directly into EHR? • Is the EHR configured as user friendly (e.g., favorite list) • Does the EHR "roll-up" the data to meet OMB and OMB/HHS requirements • Is the data used for data stratification (e.g. quality measures)	• Is the data exported / extracted to warehouse or data aggregator? • Does the data extract / export / transformation meet current ONC data exchange data requirements (HL7/CDA, UCDCI)?	• Is the aggregated data periodically validated for completeness and accuracy?

- UDS and HRSA Standards:

HRSA requires the health centers to collect and report data annually via HRSA EHB which is similar to a web-based spreadsheet. In 2024, HRSA will require an electronic feed of encounter level data from the health centers, called UDS+. This year, 2023, participation is optional and a projected requirement for 2024. Once UDS+ is implemented, it will be closely monitored and will give HRSA a greater opportunity for data analytics. HRSA will be awarding health centers that are meeting performance standards with data collection. Once the analysis begins, those that are not meeting performance standards could lose federal status and funding and could be put on a watch list.

- The UDS+ Initiative aims to reduce reporting burden, improve data quality, and better measure program services and outcomes. The goal is to expand the value and utility of UDS data for the Health Center Program while improving how health centers prepare and submit UDS data by focusing on four main areas: Reporting Modernization, Content Review, Stakeholder Engagement and Testing (11).

- Accountable Entity (AE) Pay for Performance Standards:

Managed Care / Accountable Entities are evaluated on selected quality measures. These standards do not include a demographic data collection completeness threshold or a standardized approach to demographic data collection. The Managed Care / Accountable Entities are beginning to hold back some of the payment and giving accountable care practices the opportunity to earn it through quality measure performance. The goal is for providers to provide better care at a lower cost and encourage efficiency. AE and AMO funds are based on submission performance on selected quality measures. Practices that improve quality and reduce cost are rewarded in a managed care contract through incentives. Where data is collected and reported, it must meet the ONC standards for collection and reporting of Race and Ethnicity data. The standard approach of the collection of Race and ethnicity data is the CDC code system Version 1.0 (13).

- Race and Ethnicity Data Collection and Export:

The data is being collected, however, when it is exported, many organizations are currently using a flat file export to the Quality Reporting System, and the CDC coding is getting lost. In most cases, the data is being received as text and is inconsistent with each organization. The recommendation is to configure the IMAT data extraction process to data export with data export specifications and requirements. There is some work being done to standardize the extraction process.

http://www.federalregister.gov/a/2015-25597/p-244

Recommendations & Suggested Next Steps

- **Practices should engage in discussions with their local community leaders to understand their local population.** This could include expanding the organization's board to include some local community members, forming a separate advisory board that are made up of local community members, organizing focus groups within the community to have discussions about the local demographics. Forming these groups will help to look further into the community to determine its local population. This will help to determine the best approach when engaging patients in demographic data collection.

- **Practices will then need to look at their EHR reporting capabilities and, at a minimum, consider the use of the HHS demographic categories to collect more granular data.** The HHS categories are already mapped to the OMB standards and can be re-aggregated. Most EHRs are currently working on the ability of mapping demographic data collected to the OMB categories. Currently the 1997 OMB standards are law, which is why practices must have the ability to roll up to these standards. It is required for all EHRs to have this completed prior to the end of 2023 with their CURES system update for practices to be compliant for the 2024 reporting year. Once the proposed standards become law, the roll-up will likely change to include the updates and with many other things such as quality measure reporting. Changes that need to be made also include updates to their CCD configurations to ensure that all demographic data is included when it is shared with another provider, Health Information Exchange (CurrentCare), UDS and Quality Reporting System (IMAT). Even though practices are collecting data, it is not always being shared or included in the CCDs. The CurrentCare (RIQI) HIE is configured to include race and ethnicity, but the issue is the EHR may not be configured for the transmission or sharing of this data being collected. In addition to reporting capabilities, practices /providers should also be aware and engaged in their EHR enhancements and upgrades. Practices can prepare by beginning to collect more granular data that reflects the patient community, as it will be good preparation for the transition to the new standards once they become law.

- **Practices can expand their race and ethnicity choices**. Once the local population is understood, the practice should expand their race and ethnicity choices to include the majority of their population, including race and ethnicity groups and begin to capture this data. This could be the addition of the proposed OMB standards plus additional choices that fit the practice needs. Future work will need to include mapping to the OMB standards. The expanded choices must be able to be re-aggregated (or rolled-up) to the OMB standards.

- **Patients should have the right to decline and choose more than one option**. Patients should continue to have the right to decline to answer the race or ethnicity categories, but we are hopeful with the proposed OMB standards with the option to respond to Race **OR** Ethnicity, within one combined question, will help to avoid some of the declinations. Patients should have the ability to choose one or more options if applicable. If more than one option is chosen, the practice will need to map those selections back to the OMB standards

before 2024. We are hopeful that the OMB will provide insight and support to EHR vendors and organizations with this mapping. If not, the practice will need to work with the EHR vendor and their IT/Reporting department to create the necessary mapping within the backend of the EHR so that when a report is run, the data can be displayed in granular data elements (for the practice's use) and at the OMB level for federal reporting.

- **Granular data that is collected must have the ability to be rolled up to the OMB standards**. Dr. Stella Yi's report references the Agency for Healthcare Research (AHRQ) providing some guidelines for the OMB rollup (10) and the Institute of Medicine (IOM) providing further granular guidance (11). Dr. Stella Yi recommended logic that can hide detailed race/ethnicity categories for aggregate race/ethnicity groups not selected when using an online survey tool. She recommended when utilizing a paper survey, for administration to consider how many questions are included to not overwhelm the survey respondent or staff.

- **Practices need to review all 4 areas of demographic data collection and reporting to ensure that gaps are identified and addressed.**

- **Practices need to ensure there are adequate staff and resources available to be successful with demographic data collection**. With many of the Key Informant interviews that were conducted, all practices mentioned the gap with having adequate resources and time during the patient check in process ability to obtain valid and complete demographic data from the patients. The challenge for staff is the limited time allocated to each patient with all other check-in process requirements. Workflows and resources should be reviewed and addressed at each practice to ensure that comprehensive data collection is completed. The staff should be clear about their priorities during the data collection process.

Future State Analysis

Proposed OMB Changes

The OMB initially developed the OMB Directive No. 15 to provide consistent data on race and ethnicity. There were gaps and discrepancies with the data that was being collected within practices, if it was being collected at all. Initial development stemmed from Federal responsibilities to enforce civil rights laws. Due to the continuously evolving socio-cultural attitudes toward race and ethnicity and the continuous need to maximize the quality of data by ensuring that format, language, and procedures for collecting are consistent, the OMB has proposed updates to the current standard. The current standards do not identify or designate certain population groups as "minority groups". (5) This should help to address some of the data gaps. (See diagram below and Appendix IV)

The proposal for revisions to OMB Directive No. 15 are as follows (9):
1) Collect race and ethnicity information using one combined question
   a. Should avoid respondent confusion and decrease time and resources for some surveys and information collected from patients
2) Add "Middle Eastern or North African (MENA) as a new minimum category
3) Require the collection of detailed race and ethnicity categories by default

4) Update outdated / offensive terminology
5) Guidance is necessary to implement SPD 15 revisions on federal information collections
6) Comments on any additional topics and future research
7) Offer demographic data surveys and questionnaires for the patients in languages that the community understands. I.e., Asking a patient's preferred language is recommended.

Refer to Appendix VIII for further breakdown / clarification of the revision. These proposed changes are in the Race and Ethnicity Matrix under a separate column.

The proposal closed for public comment on April 27, 2023. The OMB plans to complete the revisions before the end of summer 2024. It will take some time for the EHR vendors to make necessary updates to meet the new OMB requirements; and in turn, update their clients so that they are able to collect the demographic data and report on it.

If the proposed OMB standards have been approved, all organizations should implement the requirement to allow the additional ethnicity category of Middle Eastern / North African. Patients will then be able to choose their Race or Ethnicity, within one combined question, rather than both separately. And they should begin collecting more granular data to better understand group disparities, existing socio-economic and health disparities. It is recommended that organizations implement community outreach efforts to understand specific community needs. These efforts were also recommended from Dr. Stella Yi from New York University during a best practice key informant interview. Practices must be sure the data is collected and reflected in the services provided to their patients in a manner that is culturally appropriate. This includes the expansion of their race choices to include their patient population. For example, in some Asian cultures, spirituality is directly connected

to health, and it effects how those individuals perceive and manage their relationship with the medical community. Not all patients should be medically treated the same; it is important that organizations are educated on their patient population so they can be treated respectfully and in line with their cultural beliefs.

Practices will need direct technical assistance to support the successful implementation of these revised standards. Some practices have sophisticated technical support in-house and may seek advice on how to bridge race and ethnicity data collected under one method with data collected under a revised method. Practices without sophisticated support may need more fundamental support to implement the expanded race/ethnicity option to decrease disruption. Technical assistance should work with the practices to encourage support of system improvements and can share key findings with other organizations. (9)

CMS Medicaid
The specifications for this program regarding race and ethnicity have not yet been announced. They are expected to align with the CMS Medicare standards which follow the HHS standards and allow for granular data collection. This data will need to be re-aggregated to the OMB 2023 standards.

Conclusions

While widely adopted by multiple regulatory and certification bodies, the 1997 OMB race and ethnicity standards are generally seen as inadequate for the needs of the populations served in primary care in 2023. As we learned in the literature review, unexpected differences are seen in sub-populations. For example, while people of both eastern and western European descent may identify as Caucasian, health disparities exist between the groups. Collection of more granular data, identified with collaboration and engagement from community leaders, will provide primary care practices with the ability to understand and tailor interventions to reduce health disparities.

The gaps identified in the Race and Ethnicity Data Nodes section are gaps in data standards and data collection limit the ability of the practice and the state policy makers to fully understand their subpopulations and their associated health disparities. Organizations should review all areas of the process in order to identify and minimize any gaps. Some practices may be successful in data collection and validation but may not be able to report or meet new OMB or performance program requirements. There is no technical gap when the systems can report the collection of data internally. However, there is potentially a technical gap when sharing data with another organization or a centralized data warehouse because of the lack of data standards and sometimes onerous configuration requirements.

Organizations seeking to understand and reduce disparities and gaps in data collection should consider the following:

- Work with local community leaders to understand what sub populations are present in their community and the services they require in order to fill data gaps.
- Review the areas of data collection, data input, data extract/exporting, data validation and reporting for any gaps. All gaps should be addressed and minimized.
- At a minimum, implement the new OMB standard changes, once they are put into legislation.

- Make changes to the existing EHR to include these sub populations / granular data and expand the race category to not limit the choices to only the proposed OMB modifications (addition of Middle Eastern / North African). Also update to combine the Race and Ethnicity question to allow responders to select one or multiple options. These changes could include working with outside technical support to assist with the addition of granular data choices and the backend mapping that is required to roll up the granular data into the OMB standards.

- Update export configurations to include demographic data such as race, preferred language, sex/ gender and ethnicity. The goal is for all practices to send data in the same format. One example is the CCD. Practices need to confirm that the data that is being collected is configured for transmission and sharing.

- Update patient surveys and questionnaires to include the updated expanded options for them to understand those populations and roll them up to OMB / UDS (if FQHC).

- Educate staff on why this data is collected and how they can respectfully and sensitively assist patients and address their questions as noted in the Best Practices Literature Review.

- Educate staff on the patient population, disparities, and difference in medical needs.

- Review workflows for demographic data collection, specifically when data is collected and having a safe space for patients to complete the information. The workflow for data collection should allow for time to complete demographic data in addition to other requirements at time of check-in.

- Create reporting mechanisms that provide the roll up of granular data into the OMB standards. A clear mapping between the granular data and the OMB standards is required to understand the patient community as a whole. External technical assistance may be needed for this task based on the sophistication of in-house abilities. Since the 1997 OMB standards are law, all granular demographic data must roll up to the OMB standards for reporting. Refer to Appendix IX for IOM Recommendations for Standardized Collection of Race/Ethnicity Data

- Be aware of EHR enhancements and upgrades and the changes that will be implemented. Educate staff on enhancements and update workflows as necessary.

- The state will need to update state-wide policies to reflect all identified changes. When new OMB requirements are approved, the state will need to make updates. They could also incorporate the HHS stratification requirements.

- The state will need to have the ability to roll up any revisions or additions to meet OMB requirements.

Care Transformation Collaborative of Rhode Island (CTC-RI) Demographic Data Collection Pilot Environment Scan: Current and Anticipated Standards Requirements Summary Report

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Appendix I
Race and Ethnicity Data Standards Matrix

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See Attached Matrix

**Appendix II
1997 OMB Race and Ethnicity Stratification (Minimum Requirements)** *(1)*
Shared by Adrian Bishop

Office of Management and Budget (OMB) Standards

The Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity (OMB Statistical Policy Directive No. 15) define minimum standards for collecting and presenting data on race and ethnicity for all Federal reporting.

The race and ethnic categories are presented as separate questions, and individuals can select multiple racial categories. The OMB standards have one category for ethnicity—Hispanic or Latino—and five minimum categories for data on race. Click here for a further breakdown of each ethnic and racial group.

- **Ethnic Categories**
  - Hispanic or Latino

- **Racial Categories**
  - American Indian or Alaska Native
  - Asian
  - Black or African American
  - Native Hawaiian or Other Pacific Islander
  - White

Appendix III (4)
2011 HHS Race and Ethnicity Stratification (adopted for FQHC Reporting in 2022)
Shared by Adrian Bishop & Found on Federal Register

Ethnicity Data Standard	Categories

Are you Hispanic, Latino/a, or Spanish origin
 (One or more categories may be selected)
     a. ___No, not of Hispanic, Latino/a, or Spanish origin
     b. ___Yes, Mexican, Mexican American, Chicano/a
     c. ___Yes, Puerto Rican
	These categories roll-up to the Hispanic or Latino category of the OMB standard

Race Data Standard	Categories

What is your race?
 (One or more categories may be selected)
     a. ___White
     b. ___Black or African American
     c. ___American Indian or Alaska Native
	These categories are part of the current OMB standard

d. ___Asian Indian
     e. ___Chinese
     f. ___Filipino
     g. ___Japanese
     h. ___Korean
     i. ___Vietnamese
     j. ___Other Asian
	These categories roll-up to the Asian category of the OMB standard

k. ___Native Hawaiian
     l. ___Guamanian or Chamorro
     m. ___Samoan
     n. ___Other Pacific Islander
	These categories roll-up to the Native Hawaiian or Other Pacific Islander category of the OMB standard

Appendix IV (5)
OMB Minimum Standards vs. 2023 OMB Proposed Race and Ethnicity Stratification

Baseline (Minimum) Reporting

Addition
Detail
Optional

What is your race or ethnicity?
Select all that apply.

☐ White

☐ Hispanic or Latino

☐ Black or African American

☐ Asian

☐ American Indian or Alaska Native

☐ Middle Eastern or North African

☐ Native Hawaiian or Pacific Islander

What is your race or ethnicity?
*Select all that apply **AND** enter additional details in the spaces below. Note, you may report more than one group.*

☐ **WHITE** – *Provide details below.*
  ☐ German ☐ Irish ☐ English
  ☐ Italian ☐ Polish ☐ French
  Enter, for example, Scottish, Norwegian, Dutch, etc.
  [ ]

☐ **HISPANIC OR LATINO** – *Provide details below.*
  ☐ Mexican or Mexican American ☐ Puerto Rican ☐ Cuban
  ☐ Salvadoran ☐ Dominican ☐ Colombian
  Enter, for example, Guatemalan, Spaniard, Ecuadorian, etc.
  [ ]

☐ **BLACK OR AFRICAN AMERICAN** – *Provide details below.*
  ☐ African American ☐ Jamaican ☐ Haitian
  ☐ Nigerian ☐ Ethiopian ☐ Somali
  Enter, for example, Ghanaian, South African, Barbadian, etc.
  [ ]

☐ **ASIAN** – *Provide details below.*
  ☐ Chinese ☐ Filipino ☐ Asian Indian
  ☐ Vietnamese ☐ Korean ☐ Japanese
  Enter, for example, Pakistani, Cambodian, Hmong, etc.
  [ ]

☐ **AMERICAN INDIAN OR ALASKA NATIVE** – *Enter, for example, Navajo Nation, Blackfeet Tribe, Mayan, Aztec, Native Village of Barrow Inupiat Tribal Government, Tlingit, etc.*
  [ ]

☐ **MIDDLE EASTERN OR NORTH AFRICAN** – *Provide details below.*
  ☐ Lebanese ☐ Iranian ☐ Egyptian
  ☐ Syrian ☐ Moroccan ☐ Israeli
  Enter, for example, Algerian, Iraqi, Kurdish, etc.
  [ ]

☐ **NATIVE HAWAIIAN OR PACIFIC ISLANDER** – *Provide details below.*
  ☐ Native Hawaiian ☐ Samoan ☐ Chamorro
  ☐ Tongan ☐ Fijian ☐ Marshallese
  Enter, for example, Palauan, Tahitian, Chuukese, etc.
  [ ]

Appendix V
HHS Standards for Race and Ethnicity

Ethnicity Data Standard *Are you Hispanic, Latino/a,or Spanish Origin? (One or more categories may be selected)*

Categories	Notes
a. _____ No, not of Hispanic, Latino/a, or Spanish origin	
b. _____ Yes, Mexican, Mexican American, Chicano/a	
c. _____ Yes, Puerto Rican	These categories roll-up to the Hispanic or Latino category of the OMB standard
d. _____ Yes, Cuban	
e. _____ Yes, Another Hispanic, Latino/a or Spanish origin	

Race Data Standard *What is your race?(One or more categories may be selected)*

Categories	Notes
a. ____ White	These categories are part of the current OMB standard
b. ____ Black or African American	
c. ____ American Indian or Alaska Native	
d. ____ Asian Indian	These categories roll-up to the Asian category of the OMB standard
e. ____ Chinese	
f. ____ Filipino	
g. ____ Japanese	
h. ____ Korean	
i. ____ Vietnamese	
j. ____ Other Asian	
k. ____ Native Hawaiian	These categories roll-up to the Native Hawaiian or Other Pacific Islander category of the OMB standard
l. ____ Guamanian or Chamorro	
m. ____ Samoan	
n. ____ Other Pacific Islander	

Appendix VI
NCQA Patient Centered Medical Home Competency B

KM Competency B: Patient Diversity.

Competency B: Patient Diversity. The practice uses information about the characteristics of its patient population to provide culturally and linguistically appropriate services.

KM 09 (Core) Diversity: Assesses the diversity of its population (all items required):

A. Race.

B. Ethnicity.

C. Gender identity.

D. Sexual orientation.

E. One other aspect of diversity.

KM Competency B: Patient Diversity.

KM 11 (1 Credit) Population Needs: Identifies and addresses population-level needs based on the diversity of the practice and the community (demonstrate at least two):

A. Targets population health management on disparities in care.

B. Educates practice staff on health literacy.

C. Educates practice staff in cultural competence.

**Appendix VII
NCQA Health Equity Standard 2**

HE 2: Race/Ethnicity, Language, Gender Identity and Sexual Orientation Data

The organization gathers individuals' race/ethnicity, language, gender identity and sexual orientation data using standardized methods.

Intent

The organization collects information that helps it provide culturally and linguistically appropriate services (CLAS).

Element A: Systems for Individual-Level Data

The organization's electronic data system is able to receive, store and retrieve individual-level data on:

1. Race/ethnicity.
2. Language.
3. Gender identity.
4. Sexual orientation.

Element B: Collection of Data on Race/Ethnicity

The organization's methods for assessing race/ethnicity of individuals includes:

1. Direct collection of data from all individuals.
2. Estimation of race/ethnicity using indirect methods, if the organization has direct data on less than 80% of individuals.
3. Validation of estimation methodology, if indirect methods are used.
4. A process for rolling up race/ethnicity data to Office of Management and Budget (OMB) categories.
5. Reporting the HEDIS *Race/Ethnicity Diversity of Membership* measure, if applicable.

Element C: Collection of Data on Language

The organization's methods for assessing the language needs of individuals include:

1. Direct collection of language needs from all individuals.

2. Assessment of the population's language profile at least every three years.

3. Determination of threshold languages.

4. Determination of languages spoken by at least 1 percent of the population or 200 individuals, whichever is less.

5. Reporting the HEDIS *Language Diversity of Membership* measure, if applicable.

Element D: Collection of Data on Gender Identity

The organization's framework for collecting gender identity of individuals includes:

1. A method for collecting data that does not stigmatize individuals who do not identify as male or female.*

2. Direct collection of sex assigned at birth.

3. Direct collection of gender identity.

4. Direct collection of pronouns.

5. Sharing pronoun information with patient or member-facing staff.

Critical factors: Score cannot exceed Partially Met if one critical factor is scored "no."

Element E: Collection of Data on Sexual Orientation

The organization's framework for collecting sexual orientation information of individuals includes:

1. A method for collecting data that does not stigmatize individuals.*

2. Direct collection of data.

Critical factors: Score cannot exceed Not Met if one critical factor is scored "no."

Element F: Privacy Protections for Data

The organization has policies and procedures for managing access to and use of race/ethnicity, language, gender identity and sexual orientation data, including:

1. Controls for physical and electronic access to the data.

2. Permissible use of the data.

3. Impermissible use of the data, including underwriting and denial of coverage and benefits.

Element G: Notification of Privacy Protections

When the organization collects data from individuals, it discloses its policies and procedures for managing access to and use of race/ethnicity, language, gender identity and sexual orientation data, including:

1. Controls for physical and electronic access to the data.

2. Permissible use of the data.

3. Impermissible use of the data, including underwriting and denial of coverage and benefits.

Appendix VIII
Revisions to OMB Directive No. 15

Appendix IX
IOM Recommendations for Standardized Collection of Race/Ethnicity Data

IOM Subcommittee on Standardized Collection of Race/Ethnicity Data for Healthcare Quality Improvement: Recommendations

The IOM formed the Subcommittee on Standardized Collection of Race/Ethnicity Data for Healthcare Quality Improvement to examine approaches to the standardization of data on race, ethnicity, and language. In the 2009 report of the subcommittee, *Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement*, the IOM recommends collection of more granular ethnicity and language need according to national standards in addition to the Office of Management and Budget (OMB) race and Hispanic ethnicity categories (IOM, 2009).[1] The presence of race, ethnicity, and language need data does not, in and of itself, guarantee subsequent actions in terms of analysis of quality data to identify health care needs, or actions to reduce or eliminate disparities in health care. The absence of data, however, essentially guarantees that none of those actions will occur. The subcommittee's recommendations are presented below.

Recommendation 3-1: An entity collecting data from individuals for purposes related to health and health care should:

- Collect data on granular ethnicity using categories that are applicable to the populations it serves or studies. Categories should be selected from a national standard list (*see Recommendation 6-1a*) on the basis of health and health care quality issues, evidence or likelihood of disparities, or size of subgroups within the population. The selection of categories should also be informed by analysis of relevant data (e.g., Census data) on the service or study population. In addition, an open-ended option of "Other, please specify:__" should be provided for persons whose granular ethnicity is not listed as a response option.
- Elicit categorical responses consistent with the current OMB standard race and Hispanic ethnicity categories, with the addition of a response option of "Some other race" for persons who do not identify with the OMB race categories.

Recommendation 3-2: Any entity collecting data from individuals for purposes related to health and health care should collect granular ethnicity data in addition to data in the OMB race and Hispanic ethnicity categories and should select the granular ethnicity categories to be used from a national standard set. When respondents do not self-identify as one of the OMB race categories or do not respond to the Hispanic ethnicity question, a national scheme should be used to roll up the granular ethnicity categories to the applicable broad OMB race and Hispanic ethnicity categories to the extent feasible.

Recommendation 3-3: To determine the utility for health and health care purposes, HHS should pursue studies on different ways of framing the questions and related response categories for collecting race and ethnicity data at the level of the OMB categories, focusing on completeness and accuracy of response among all groups.

- Issues addressed should include use of the one- or two-question format for race and Hispanic ethnicity, whether all individuals understand and identify with the OMB race and Hispanic ethnicity categories, and the increasing size of populations identifying with "Some other race."
- The results of such studies, together with parallel studies by the Census Bureau and other agencies, may reveal the need for an OMB review across all agencies to determine the best format for improving response among all groups.

Recommendation 4-1: To assess patient/consumer language and communication needs, all entities collecting data from individuals for purposes related to health and health care should:

- At a minimum, collect data on an individual's assessment of his/her level of English proficiency and on the preferred spoken language needed for effective communication with health care providers. For health care purposes, a rating of spoken English-language proficiency of less than very well is considered limited English proficiency.
- Where possible and applicable, additionally collect data on the language spoken by the individual at home and the language in which he/she prefers to receive written materials.

Recommendation 4-2: The choice of response categories for spoken and written language questions should be informed by analysis of relevant data on the service area (e.g., Census data) or service population, and any response list should include an option of "Other, please specify:__" for persons whose language is not listed.

Recommendation 4-3: When any health care entity collects language data, the languages used as response options or categories for analysis should be selected from a national standard set of languages in use in the United States. The national standard set should include sign language(s) for spoken language and Braille for written language.

Recommendation 5-1: Where directly collected race and ethnicity data are not available, entities should use indirect estimation to aid in the analysis of racial and ethnic disparities and in the development of targeted quality improvement strategies, recognizing the probabilistic and fallible nature of such indirectly estimated identifications.

- Race and ethnicity identifications based on indirect estimation should be distinguished from self-reports in data systems, and if feasible, should be accompanied by probabilities.
- Interventions and communications in which race and ethnicity identifications are based on indirect estimation may be better suited to population-level interventions and communications and less well suited to use in individual-level interactions.
- An indirectly estimated probability of an individual's race and ethnicity should never be placed in a medical record or used in clinical decision making.
- Analyses using indirectly estimated race and ethnicity should employ statistically valid methods that deal with probabilistic identifications.

Recommendation 6-1a: HHS should develop and make available national standard lists of granular ethnicity categories and spoken and written languages, with accompanying unique codes and rules for rollup procedures.

- HHS should adopt a process for routine updating of those lists and procedures as necessary. Sign languages should be included in national lists of spoken languages and Braille in lists of written languages.

- HHS should ensure that any national hierarchy used to roll up granular ethnicity categories to the broad OMB race and Hispanic ethnicity categories takes into account responses that do not correspond to one of the OMB categories.

Recommendation 6-1b: HHS and the Office of the National Coordinator for Health Information Technology (ONC) should adopt standards for including in electronic health records the variables of race, Hispanic ethnicity, granular ethnicity, and language need identified in this report.

Recommendation 6-1c: HHS and ONC should develop standards for electronic data transmission among health care providers and plans that support data exchange and possible aggregation of race, Hispanic ethnicity, granular ethnicity, and language need data across entities to minimize redundancy in data collection.

Recommendation 6-1d: The Centers for Medicare and Medicaid Services, as well as others sponsoring payment incentive programs, should ensure that the awarding of such incentives takes into account collection of the recommended data on race, Hispanic ethnicity, granular ethnicity, and language need so these data can be used to identify and address disparities in care.

Recommendation 6-1e: HHS should issue guidance that recipients of HHS funding (e.g., Medicare, the Children's Health Insurance Program [CHIP], Medicaid, community health centers) include data on race, Hispanic ethnicity, granular ethnicity, and language need in individual health records so these data can be used to stratify quality performance metrics, organize quality improvement and disparity reduction initiatives, and report on progress.

Recommendation 6-2: HHS, the Department of Veterans Affairs, and the Department of Defense should coordinate their efforts to ensure that all federally funded health care delivery systems collect the variables of race, Hispanic ethnicity, granular ethnicity, and language need as outlined in this report, and include these data in the health records of individuals for use in stratifying quality performance metrics, organizing quality improvement and disparity reduction initiatives, and reporting on progress.

Recommendation 6-3: Accreditation and standards-setting organizations should incorporate the variables of race, Hispanic ethnicity, granular ethnicity, and language need outlined in this report and associated categories (as updated by HHS) as part of their accreditation standards and performance measure endorsements.

- The Joint Commission, NCQA, and URAC should ensure collection in individual health records of the variables of race, Hispanic ethnicity, granular ethnicity, and language need as outlined in this report so these data can be used to stratify quality performance metrics, organize quality improvement and disparity reduction initiatives, and report on progress.
- NQF should review and amend its recommendations on the collection and use of data on race, Hispanic ethnicity, granular ethnicity, and language need to accord with the categories and procedures outlined in this report.
- Medical societies and medical boards should review and endorse the variables, categories, and procedures outlined in this report and educate their members on their use for quality improvement.

Recommendation 6-4: Through their certification, regulation, and monitoring of health care providers and organizations within their jurisdiction, states should require the collection of data on the race, Hispanic ethnicity, granular ethnicity, and language need variables as outlined in this report so these data can be used

to stratify quality performance metrics, organize quality improvement and disparity reduction initiatives, and report on progress.