# Massachusetts Quality Measure Alignment Taskforce

## Recommended Health Equity Data Standards

July 1, 2022

## Introduction

In fall 2021, the Massachusetts Executive Office of Health and Human Services (EOHHS) established the Health Equity Technical Advisory Groups as subgroups of the Quality Measure Alignment Taskforce (Taskforce). There were two Advisory Groups: the Accountability Advisory Group and the Data Standards Advisory Group. The Accountability Advisory Group met from January to June 2022 to develop principles for introducing accountability for health equity measures into global budget-based risk contracts (such as MassHealth and commercial ACO contracts). The Data Standards Advisory Group met from January to June 2022 to develop an aligned approach to standardized data collection for health equity data, i.e., race, ethnicity, language, disability status, sexual orientation, gender identity and sex) for use by all payers and providers in the Commonwealth. A list of the Data Standards Advisory Group members can be found in the Appendix.

This document summarizes the Taskforce’s health equity data standards recommendations after consideration of those put forth by the Data Standards Advisory Group, as well as suggested next steps to support refinement and implementation of the data standards recommendations.

## Overview of Sources for the Recommended Data Standards

|  |  |
| --- | --- |
| **Data Standard** | **Standard Source(s)** |
| Race | Office of Management and Budget |
| Ethnicity | Office of Management and Budget  |
| Granular Ethnicity | Massachusetts Superset |
| Language | American Hospital Association Institute for Diversity and Health Equity **or** Edward M Kennedy Community Health Center; American Community Survey data for languages spoken by at least 0.5% of the Massachusetts population  |
| Disability | Oregon Health Authority |
| Sexual Orientation | Centers for Disease Control and Prevention |
| Gender Identity | Oregon Health Authority |
| Sex | Oregon Health Authority |

**Data Standards on Race, Ethnicity, and a Third Variable**

The Advisory Group discussed how the Office of Management and Budget (OMB) data standards do not accurately describe how people self-identify their race and ethnicity. In addition, members agreed that OMB race and ethnicity standards are not granular enough for payers and providers to identify and intervene on health inequities. When considering alternative standards, such as the federal Health and Human Services and 2020 Census standards, the group found them to incorrectly identify ethnicities as races.

For these reasons, the Advisory Group supported the use of “granular ethnicity[[1]](#footnote-2)” as a third variable for measuring ethnicity. It recommended using the Massachusetts Superset[[2]](#footnote-3) as a source for granular ethnicity categories because:

1. use of the Superset builds off prior state initiatives;
2. the Superset was designed to reflect the Massachusetts population;
3. although FHIR includes a lengthy list of ethnicities, it is not inclusive of all of the most significant ethnic populations residing in Massachusetts (e.g., Portuguese, Cape Verdean, Russian), and
4. there were operational feasibility concerns associated with implementing FHIR due to the large number of ethnicities contained within it.

**The final recommendations for data standards for use by all payers and providers in the Commonwealth as endorsed by the Taskforce are:**

1. Payers and providers should collect race and ethnicity using the minimum OMB standards, while FHIR categories should be used as the standard for data storage and exchange.
2. Payers and providers should collect granular ethnicity using the main ethnicities included in the Superset.
	1. The Superset can be used as constructed. EOHHS, however, should:
		1. evaluate whether the Superset needs to be updated in the future to accurately reflect the current state population and
		2. determine whether “American” should be removed or more clearly defined as a granular ethnicity option.
	2. For data storage, granular ethnicities should be recorded using the existing FHIR categories, be they considered a race or ethnicity by FHIR.
	3. Superset granular ethnicities that are not included in FHIR (American, Brazilian, Cape Verdean, Caribbean Islander, Eastern European, Portuguese, and Russian) should not be mapped to FHIR categories and granular ethnicities with no determinate OMB classification (American, Brazilian, Cape Verdean, Dominican) should not be mapped to an OMB category. Rather, these granular ethnicities should each be stored in a customized category.
3. Payers and providers may individually supplement the required granular ethnicity member/patient-level categories by adding additional granular ethnicitiesthat are relevant to their member/patient population.

**Additional implementation considerations for the collection of race, ethnicity, and granular ethnicity data include:**

* The minimum OMB race or ethnicity into which a selected granular ethnicity aggregates will not always match the minimum OMB race or ethnicity that an individual selected for themselves.
* Payers and provider organizations will need to determine how they will store those granular ethnicities that:
	+ are included in FHIR but have no determinate OMB classification (Dominican);
	+ have a determinate OMB classification but are not included in FHIR (Eastern European, Portuguese, and Russian), or
	+ are not included in FHIR *and* have no determinate OMB classification (American, Brazilian, Cape Verdean).
* EOHHS should determine how to store data for individuals who identify with multiple races and/or granular ethnicities.
* EOHHS should engage a survey design expert to develop questions to be used for the collection of race, ethnicity, and granular ethnicity data.

**Data Standards on Sexual Orientation, Gender Identity, and Sex**

***Sexual orientation***: Advisory Group members supported combining the Oregon Health Authority (OHA) and FHIR data standards in order to provide the most detailed set of response options for sexual orientation. Advisory Group members did not provide specific instructions for how this combination should occur.[[3]](#footnote-4) EOHHS expressed concerns about the complexity of combining two data standards and shared a preference for alignment with a national categorization system, if possible. Advisory Group members stated that while they preferred OHA’s standard, they found the CDC standard for sexual orientation to be an acceptable alternative given the presence of a write-in option. The Taskforce subsequently recommended use of the CDC standard.

***Gender identity***: Despite EOHHS’ preference for a national categorization system, the Advisory Group, and subsequently the Taskforce, maintained their support for the OHA data standard for gender identity because:

1. OHA includes a separate question about transgender identity. A transgender respondent may identify as transgender *and* female or male (or neither female nor male), which would not be captured by the other data standards. The Advisory Group also thought that the wording of other data standards’ response options on transgender identity were not affirming (e.g., “Transgender Man / Transgender Male,” “Transgender Woman / Transgender Female”);
2. OHA allows for the selection of multiple genders, and
3. OHA uses man/woman instead of male/female. Male/female terms are more often used to refer to sex than gender identity.

***Sex***: Despite EOHHS’ preference for a national categorization system, Advisory Group members and subsequently the Taskforce maintained their support for the OHA data standard for sex. Two Advisory Group members suggested modifying the first OHA question from “When you were born what biological sex was assigned to you?” to “What was your sex assigned at birth,” with “x” and “intersex” added as response options.[[4]](#footnote-5)

* Should the OHA standards be used for sex, EOHHS would need to determine:
	1. which OHA sex question (or both) should be adopted, as OHA includes two different options;
	2. whether the legal sex response options in Massachusetts are the same as those in Oregon if the legal sex question is used, and
	3. whether the OHA standards should be adopted as is, or modified per the recommendation from two members as described above if the assigned sex question is used.

*Sexual Behavior and Pronouns:* The Advisory Group recommended that data standards also be adopted for sexual behavior and pronouns. Given the ambitious agenda and limited duration of the Advisory Group, this question was not considered by the group. Therefore, payers and providers are encouraged to collect data on sexual behavior and pronouns on an optional and voluntary basis.

**Additional recommendations related to SOGIS data standards include:**

1. Data collection should start between ages 11 and 13 but should be optional until age 16.
2. Because member/patient self-reported SOGIS may change over time, particularly for youth, payers and provider organizations should collect data at least annually.
3. EOHHS should disseminate instructions that SOGIS data must be collected through patient self-report, that data collection must include opt-out options, and that health plan/provider staff should never assume a member/patient’s sexual orientation, gender identity, or sex.

**Additional implementation considerations for the collection of SOGIS data include:**

1. Payers and provider organizations will need to determine how to collect SOGIS data from pediatric populations, including how/if to engage parents in data collection.

**Data Standards on Language**

Advisory Group members expressed a desire for questions that were not “English-centric,” and believed it to be important to ask about both written and spoken language preferences. Members also recommended questions ask about language preference as it relates to health care information specifically. Members were divided between two similar sets of questions and did not make a consensus recommendation for this reason. The Taskforce recommended that the final determination on language questions be made by a consulting survey design expert.

The first set of questions were from the American Hospital Association (AHA) Institute for Diversity and Health Equity. These questions read:

1. What language do you feel most comfortable speaking with your doctor or nurse?
2. In which language would you feel most comfortable reading medical or health care instructions?
* Advisory Group members suggested replacing “doctor or nurse” in question one with something broader. Suggestions included using “medical provider” instead, or rewording the question to frame it as simply asking which language is preferred when discussing one’s health or health care. Advisory Group members also suggested replacing “health care instructions” in question two with “health care information.”

The second set of questions were from the Edward M. Kennedy Community Health Center (Kennedy CHC). Advisory Group members liked the following two questions from this set:

1. In what language do you prefer to discuss your health?
2. In what language do you prefer to read health information?

Advisory Group members supported using a short list of language options as the minimum required data standard but were divided on how short the list should be. Members supported either using a list of languages spoken by at least 1% of the Massachusetts population or at least 0.5% of the Massachusetts population, per the latest American Community Survey (ACS) results. In either scenario, members requested an additional write-in option of “Other language (please specify)” as part of the standard, and members also recommended that “Sign Language, such as ASL” be included as an option. The Taskforce subsequently recommended using the list of languages spoken by at least 0.5% of the Massachusetts population.

The languages that are spoken by at least 0.5% of the Massachusetts population include English, Spanish, Portuguese, Chinese, Haitian, French, Vietnamese, Russian, and Arabic.

Advisory Group members recommended that patients only be permitted to select one preferred language.

**Additional implementation considerations for the collection of language data include:**

1. Some languages will require nuanced differences in the options presented for spoken and written language preference (e.g., for Chinese written language it is necessary to ask for preference for simplified vs traditional characters).
2. Prior to standards implementation, consideration should be given to:
	1. whether to group certain languages together (e.g., Cantonese and Mandarin as “Chinese,” Cape Verdean Creole as “Portuguese”);
	2. how to collect language preferences for pediatric and geriatric populations since there may be multiple caregivers with different language preferences.

**Data Standards on Disability Status**

Advisory Group members considered several disability data standards, most of which had considerable overlap. Ultimately, the Advisory Group was split between two similar data standards which primarily contain questions developed for populations age five and older. The first data standard is a hybrid of the Health and Human Services (HHS) and Washington Group on Disability Statistics standards that the Health Information Technology Advisory Committee has recommended to the Office of the National Coordinator for Health Information Technology (ONC) for use in United States Core Data Interoperability – Version 3 standards (USCDI v3). The second data standard builds upon USCDI v3, adding two questions developed by the Oregon Health Authority. Several Advisory Group members voiced support for the additional learning and mood-focused questions added by Oregon, while others preferred the unaltered USCDI v3 recommendations, believing that there was improved likelihood of EHR implementation and interoperability of such standards. The Taskforce subsequently recommended use of the Oregon Health Authority standards.

Advisory Group members recommended against a separate disability standard specific to children younger than five years old. Members made this recommendation reluctantly, expressing frustration that a separate standard did not exist to support efficient and effective identification of disability status for children younger than five years old without the use of diagnostic codes. Members suggested that disability data standards for young children be revisited in the future when new standards may exist. Members also noted that most ACOs would have small numbers of patients should there be a separate standard for young children with disabilities.

Advisory Group members also recommended against the use of any tool that uses ICD codes to determine disability status for young children (e.g., the Children with Disabilities Algorithm). Members recommended that whatever disability data standard is adopted be used according to the specified age cut-offs.

Finally, a Taskforce member suggested that a survey design consultant advise on inclusion of a question that asks whether a respondent had help, and if so, what kind of help, to respond to the questions outlined in the Oregon Health Authority disability standard.

**Additional implementation considerations for the collection of disability data include:**

1. Individuals that screen positive for a disability through the recommended data standards may not consider themselves as having a disability.

**Additional Implementation Considerations for *All* Data Standards**

The Advisory Group discussed which *non-response* and *“choose-not-to-answer”* option(s) should be used within the data standards (including “I prefer not to say” or “I choose not to answer”, “I am not sure”, “My (race, ethnicity, language, etc.) is not listed” and “Unable to obtain”) and eventually agreed to recommend that a survey design expert be engaged to:

* 1. provide feedback on the proposed *non-response* and *“choose-not-to-answer”* option(s)*;*
	2. develop a non-response option(s) for data collection that can be applied for member/patient interviews;
	3. ensure that the recommended *non-response* and *“choose-not-to-answer”* options map to FHIR, and
	4. ensure that the same *non-response* and “*choose-not-to-answer*” options can be consistently applied across all data standards.

In addition, prior to standards implementation, the Advisory Group highlighted that consideration should be given to:

1. how to train staff to collect data from members/patients and incorporate the data standards into workflows;
2. how to explain to members/patients how the social risk factors being collected are defined and why they are being collected. This is particularly relevant for granular ethnicity, sexual orientation, gender identity, and sex;
3. how to determine at what age children should answer questions on their own as well as who can answer questions on behalf of young children;
4. how frequently to collect these data, which may vary by data standard;
5. how the data standards map to the Health Resources Service Administration data standards to enable Federally Quality Health Centers to comply with federal reporting requirements, and
6. how to facilitate data sharing between payers and providers to avoid unnecessary re-screening of members/patients.

**Appendix A: Table of Recommended Health Equity Data Standards**

**Race (OMB)**

| **Question(s)** | **Response Options** | **Notes** |
| --- | --- | --- |
| Not specified. | * American Indian or Alaska Native
* Asian
* Black or African American
* Native Hawaiian or Other Pacific Islander
* White
 | -Multiple races can be selected-Question language as well as non-response and choose-not-to-answer options will be determined in consultation with a survey expert |

**Ethnicity (OMB)**

| **Question(s)** | **Response Options** | **Notes** |
| --- | --- | --- |
| Not specified. | * Hispanic or Latino
* Not Hispanic or Latino
 | -Question language as well as non-response and choose-not-to-answer options will be determined in consultation with a survey expert |

**Granular Ethnicity (Massachusetts Superset)**

| **Question(s)** | **Response Options** | **Notes** |
| --- | --- | --- |
| Not specified, but must be asked separately from race and ethnicity.  | * African
* African American
* American
* Asian Indian
* Brazilian
* Cambodian
* Cape Verdean
* Caribbean Islander
* Central American
* Chinese
* Colombian
* Cuban
* Dominican
* Eastern European
* European
* Filipino
* Guatemalan
* Haitian
* Honduran
* Japanese
* Korean
* Laotian/Lao
* Mexican
* Middle Eastern or North African
* Portuguese
* Puerto Rican
* Russian
* Salvadoran
* South American
* Vietnamese
* Other Ethnicity
 | -Question language as well as non-response and choose-not-to-answer options will be determined in consultation with a survey expert |

**Language (AHA or Kennedy CHC, and ACS data for languages spoken by at least 0.5% of the Massachusetts population)**

| **Question(s)** | **Response Options** | **Notes** |
| --- | --- | --- |
| **Spoken Language Option 1 (AHA):**What language do you feel most comfortable speaking with your doctor or nurse?**Spoken Language Option 2 (Kennedy CHC):**In what language do you prefer to discuss your health? | * English
* Spanish
* Portuguese
* Chinese
* Haitian
* Sign Language, such as ASL
* Other (please specify)French
* Vietnamese
* Russian
* Arabic
 | -Question language as well as non-response and choose-not-to-answer options will be determined in consultation with a survey expert-Advisory Group members suggested changing “doctor or nurse” in option 1 to something more generic-Chinese could be separated into Cantonese and Mandarin and Cape Verdean Creole could be separated from Portuguese |
| **Written Language Option 1 (AHA):**In which language would you feel most comfortable reading medical or health care instructions?**Written Language Option 2 (Kennedy CHC):**In what language do you prefer to read health information? | * English
* Spanish
* Portuguese
* Chinese (please specify traditional or simplified)
* Haitian
* Other, please specify French
* Vietnamese
* Russian
* Arabic
 | -Question language as well as non-response and choose-not-to-answer options will be determined in consultation with a survey expert-Members suggested changing “health care instructions” in option 1 to “health care information” -Chinese could be separated into Cantonese and Mandarin and Cape Verdean Creole could be separated from Portuguese |

**Sexual Orientation (CDC)**

| **Question(s)** | **Response Options** | **Notes** |
| --- | --- | --- |
| Do you think of yourself as: | * Straight or heterosexual
* Lesbian or gay
* Bisexual
* Queer, pansexual, and/or questioning
* Something else; please specify
* Don’t know
* Decline to answer
 | -Non-response and choose-not-to-answer options may be modified for consistency across data standards after consultation with a survey expert |

**Gender (OHA)**

| **Question(s)** | **Response Options** | **Notes** |
| --- | --- | --- |
| 1. What is your gender? | * Woman/girl
* Man/boy
* Non-binary
* Agender/no gender
* Questioning
* Not listed. Please specify
* Don’t know
* I don’t know what this question is asking
* I don’t want to answer
 | -Respondents may check all that apply-Non-response and choose-not-to-answer options may be modified for consistency across data standards after consultation with a survey expert |
| 2. Are you transgender? | * Yes
* No
* Don’t know
* Questioning[[5]](#footnote-6)
* I don’t know what this question is asking
* I don’t want to answer
 | -Non-response and choose-not-to-answer options may be modified for consistency across data standards after consultation with a survey expert |

**Sex (OHA)**

| **Question(s)** | **Response Options** | **Notes** |
| --- | --- | --- |
| **OHA Option 1:**When you were born what biological sex was assigned to you? (Pick one) | * Male
* Female
* Intersex[[6]](#footnote-7)
* Unspecified
* Don’t know
* Not listed. Please specify
* I don’t know what this question is asking
* I don’t want to answer
 | -Non-response and choose-not-to-answer options may be modified for consistency across data standards after consultation with a survey expert-Some members recommended rewording the question to “What was your sex assigned at birth?” and adding “X” as a response option |
| **OHA Option 2:** What is your current legal sex in your state? (Pick one) OR simply: What is your current sex?[[7]](#footnote-8) | * Male
* Female
* X[[8]](#footnote-9)
* Intersex
* Non-binary
* Unspecified
* Don’t know
* Not listed. Please specify
* I don’t know what this question is asking
 | -Non-response and choose-not-to-answer options may be modified for consistency across data standards after consultation with a survey expert |

**Disability (OHA)**

| **Question(s)** | **Response Options** | **Notes** |
| --- | --- | --- |
| 1. Are you deaf or do you have serious difficulty hearing? | * Yes
* No
* Declined
* Unknown
* I do not know what this question is asking
 | -**No age threshold**-Non-response and choose-not-to-answer options may be modified for consistency across data standards after consultation with a survey expert |
| 2. Are you blind or do you have serious difficulty seeing, even when wearing glasses? | * Yes
* No
* Declined
* Unknown
* I do not know what this question is asking
 | -**No age threshold**-Non-response and choose-not-to-answer options may be modified for consistency across data standards after consultation with a survey expert |
| 3. Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions? | * Yes
* No
* Declined
* Unknown
* I do not know what this question is asking
 | -Question applies to those **5 years or older** -Non-response and choose-not-to-answer options may be modified for consistency across data standards after consultation with a survey expert |
| 4. Do you have serious difficulty walking or climbing stairs?  | * Yes
* No
* Declined
* Unknown
* I do not know what this question is asking
 | -Question applies to those **5 years or older** -Non-response and choose-not-to-answer options may be modified for consistency across data standards after consultation with a survey expert |
| 5. Do you have difficulty dressing or bathing?  | * Yes
* No
* Declined
* Unknown
* I do not know what this question is asking
 | -Question applies to those **5 years or older** -Non-response and choose-not-to-answer options may be modified for consistency across data standards after consultation with a survey expert |
| 6. Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor’s office or shopping? | * Yes
* No

 * Declined
* Unknown
* I do not know what this question is asking
 | -Question applies to those **15 years or older** -Non-response and choose-not-to-answer options may be modified for consistency across data standards after consultation with a survey expert |
| 7. Using your usual (customary) language, do you have difficulty communicating, (for example understanding or being understood by others)?  | * Yes
* No
* Declined
* Unknown
* I do not know what this question is asking
 | -Question applies to those **5 years or older** -Non-response and choose-not-to-answer options may be modified for consistency across data standards after consultation with a survey expert |
| 8. Do you have serious difficulty learning how to do things most people your age can learn?  | * Yes
* No
* Declined
* Unknown
* I do not know what this question is asking
 | -Question applies to those **5 years or older** -Non-response and choose-not-to-answer options may be modified for consistency across data standards after consultation with a survey expert |
| 9. Do you have serious difficulty with the following: mood, intense feelings, controlling your behavior, or experiencing delusions or hallucinations?  | * Yes
* No
* Declined
* Unknown
* I do not know what this question is asking
 | -Question applies to those **15 years or older** -Non-response and choose-not-to-answer options may be modified for consistency across data standards after consultation with a survey expert |

**Appendix B: Data Standards Advisory Group Members**

* Jessiaha Adamopoulos (Massachusetts Behavioral Health Partnership)
* Susan Adams (Massachusetts League of Community Health Centers)
* Renee Altman-Nefussy (Point32Health)
* William Atkinson (Mercy Medical Center)
* Cheri Blauwet (Spaulding Rehabilitation Hospital)
* Rosa Colon-Kolacko (Wellforce and Tufts Medical Center)
* Tiffany Cook (University of Massachusetts Chan Medical School)
* Leena El-Mufti (Commonwealth Care Alliance)
* Danielle Funk (Fenway Health)
* Arvin Garg (University of Massachusetts Memorial Health Care System)
* Esteban Greshanik (Brigham and Women’s Hospital)
* Lisa Iezzoni (Harvard Medical School)
* Mitchell Izower (Meditech)
* Jonathan Lichkus (Greater Lawrence Family Health Center)
* Mark Mandell (Steward Health Network)
* Scott Minkin (Health Leads)
* Sylvia Odiana (Beth Israel Lahey Health)
* Barbra Rabson (Massachusetts Health Quality Partners)
* Natalia Rodriguez (Community Care Cooperative)
* Kristine Sand (Blue Cross Blue Shield of Massachusetts)
* Judith Savageau (University of Massachusetts Chan Medical Center)
* Sue Schlotterbeck (Edward M. Kennedy Community Health Center)
* Snehal Shah (Boston Children’s Hospital)
* Amy Sousa (The Guild for Human Services)
* Tiffany Stack (Boston Medical Center)
1. Granular ethnicity is defined as “a person’s ethnic origin or descent, ‘roots,’ or heritage, or the place of birth of the person or the person’s parents or ancestors.” [↑](#footnote-ref-2)
2. The Massachusetts Superset was created by a DPH-led workgroup following a 2007 state regulation that mandated all acute-care hospitals in Massachusetts collect ethnic background data. That workgroup developed the Superset to be representative of the Massachusetts population and thus includes 31 main ethnic backgrounds, which generally roll up to the OMB race and ethnicities, though some are not found in FHIR. Additional information can be found here: <https://www.nap.edu/catalog/12696/race-ethnicity-and-language-data-standardization-for-health-care-quality> [↑](#footnote-ref-3)
3. Some response options included within OHA are not included within FHIR, including “same-gender loving,” “same-sex loving,” and “pansexual.” In addition, one of FHIR’s response options is “multiple sexual orientations,” whereas OHA directs respondents to “check all [sexual orientations] that apply.” [↑](#footnote-ref-4)
4. OHA has added “intersex” as a response option to this question since the Advisory Group discussed it. OHA’s most recent draft standards can be found here: <https://www.oregon.gov/oha/OEI/Documents/Draft-SOGI-Data-Recommendations.pdf> and additional changes to OHA’s standards are noted in the appendix of this document. [↑](#footnote-ref-5)
5. At the time the Advisory Group discussed these standards, OHA’s (since updated) draft standards included “Not listed. Please specify” as a response option instead of “Questioning.” [↑](#footnote-ref-6)
6. At the time the Advisory Group discussed these standards, OHA’s (since updated) draft standards did not include “Intersex” as a response option. However, the Advisory Group recommended that “Intersex” be added as a response option to this question. [↑](#footnote-ref-7)
7. OHA lists this as an alternate way to ask this question. However, this alternate question was not put before the Advisory Group for discussion. [↑](#footnote-ref-8)
8. At the time the Advisory Group discussed these standards, OHA’s (since updated) draft standards did not include “X” as a response option to this question. The Advisory Group recommended adding “X” as a response option to question option 1, but did not specifically recommend that it be added as a response option to this question. [↑](#footnote-ref-9)