Massachusetts Quality Measure Alignment Taskforce
Health Equity Data Standards
March 2023 Update

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 Data Standards Advisory Group met from February to June 2022 to develop an aligned approach to standardized data collection for 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.

The Taskforce first reviewed and provided feedback on the Data Standards Advisory Group's recommendations in June 2022. EOHHS then posted the draft data standards for public comment in July 2022. The Taskforce received 18 distinct submissions weighing in on the draft data standards and processed this feedback during its September 2022 meeting. The Taskforce discussed the data standards once more in November 2022 in order to align its standards with those proposed by MassHealth to the fullest extent possible to minimize complications for provider and payer data workflows.

In addition, EOHHS sought input from a firm with survey expertise to resolve questions related to wording choices used when asking people to share their race, ethnicity, language, disability, sexual orientation, gender identity, and sex data. Massachusetts Health Quality Partners (MHQP) was contracted to complete this work between July and September 2022. MHQP completed 20 semi-structured cognitive interviews with individuals of diverse backgrounds to inform its recommendations.

This document summarizes the Taskforce's final health equity data standards after consideration of the Data Standards Advisory Group's and MHQP's work, as well as input from the public and the Taskforce itself. This document also highlights important considerations for the implementation of the data standards. The effective date of these data standards shall be considered January 1, 2023, and the Taskforce recommends implementation of the race, ethnicity (including granular ethnicity), and language data standards within one year of this effective date (i.e., by January 1, 2024), and implementation of the disability, sexual orientation, gender identity, and sex data standards within two years of this date (i.e., by January 1, 2025).

These data standards are intended to serve as minimum required standards. Organizations are welcome and encouraged to ask additional questions and/or collect additional response option values as relevant for the populations they serve.

These data should be collected (or validated with the member/patient) at least annually, with the potential for greater frequency for particular data standards at the discretion of the payer or provider organization.

Overview of Sources[1] for the Data Standards

Data Standard	Standard Source(s)
Race	Office of Management and Budget (OMB)
Ethnicity	Office of Management and Budget
Granular Ethnicity	Massachusetts Department of Public Health
Language	American Hospital Association Institute for Diversity and Health Equity; U.S. Census Bureau (2019 American Community Survey data for languages spoken by at least 0.5% of the Massachusetts population)
Disability	U.S. Department of Health and Human Services (HHS)
Sexual Orientation	Centers for Disease Control and Prevention
Gender Identity	Centers for Disease Control and Prevention
Sex	Oregon Health Authority

Health Equity Data Standards

Race (Office of Management and Budget)

Question(s)	Response Options	Notes
What is your race? Check all that apply.	▪ American Indian or Alaska Native ▪ Asian ▪ Black or African American ▪ Native Hawaiian or Other Pacific Islander ▪ White ▪ My race is not listed (please specify) ▪ I choose not to answer ▪ I am not sure / don't know	

Ethnicity (Office of Management and Budget)

Question(s)	Response Options	Notes
Are you of Hispanic or Latino origin or descent?	▪ Hispanic or Latino ▪ Not Hispanic or Latino ▪ I choose not to answer ▪ I am not sure / don't know	

[1] The recommendations herein were informed by the standards listed for each source as of June 2022. For those standards that already included "non-response" and choose-not-to-answer options, slight modifications were made to these responses to align the options across the data standards with those recommended by MHQP.

Granular Ethnicity[2] (Massachusetts Department of Public Health[3])

Question(s)	Response Options	Notes
What is your ethnicity? Check all that apply.	▪ 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 ▪ My ethnicity is not listed (please specify) ▪ I choose not to answer ▪ I am not sure / don't know	The Massachusetts Superset should be used as constructed; EOHHS may evaluate whether the Superset needs to be updated in the future. For data storage, granular ethnicities should be recorded using the existing FHIR categories, be they considered a race or ethnicity by FHIR. Superset granular ethnicities with no determinate OMB classification (American, Brazilian, Cape Verdean, Dominican) should not be mapped to a minimum OMB category. Likewise, 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. Rather, these granular ethnicities should each be stored in a customized category.

[2] 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."

[3] The Massachusetts Superset (Superset) was created by a Department of Public Health-led work group following a 2007 state regulation that mandated all acute-care hospitals in Massachusetts collect ethnic background data. That work group 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

Language (American Hospital Association Institute for Diversity and Health Equity; U.S. Census Bureau (2019 American Community Survey data for languages spoken by at least 0.5% of the Massachusetts population))

Question(s)	Response Options	Notes
Spoken Language: What language do you feel most comfortable speaking with your doctor or nurse?	▪ English ▪ Spanish ▪ Portuguese ▪ Chinese ▪ Haitian ▪ Sign Language, such as ASL ▪ French ▪ Vietnamese ▪ Russian ▪ Arabic ▪ My language is not listed (please specify) ▪ I choose not to answer ▪ I am not sure / don't know	Organizations may decide to separate "Chinese" into "Cantonese" and "Mandarin[4]." Organizations may decide to include "Cape Verdean Creole[5]" as a separate option from "Portuguese" for spoken language.
Written Language: In which language would you feel most comfortable reading medical or health care instructions?	▪ English ▪ Spanish ▪ Portuguese ▪ Chinese (please specify traditional or simplified) ▪ Haitian ▪ French ▪ Vietnamese ▪ Russian ▪ Arabic ▪ My language is not listed (please specify) ▪ I choose not to answer ▪ I am not sure / don't know	For written language, organizations should <u>not</u> include "Cape Verdean Creole" as a separate option from "Portuguese[6]."

[4] American Community Survey data indicated that 2+% of Massachusetts residents speak Chinese. The data did not indicate what percentage speak Cantonese vs Mandarin.
[5] American Community Survey data indicated 3+% of the Massachusetts population speak Portuguese. The data did not separately indicate the percentages for Cape Verdean Creole vs traditional Portuguese.
[6] Because of variations in the written format of Cape Verdean Creole, it has not yet been established as an official written language.

Sexual Orientation (Centers for Disease Control and Prevention)

Question(s)	Response Options	Notes
Which of these best describes your current sexual orientation? Check all that apply.[7]	▪ Straight or heterosexual ▪ Lesbian or gay ▪ Bisexual ▪ Queer, pansexual, and/or questioning ▪ My sexual orientation is not listed (please specify) ▪ I choose not to answer ▪ I am not sure / don't know	Data collection should start between ages 11 and 13 but should be optional until 16. Data must be collected through patient self-report and health plan/provider staff should never assume a member/patient's sexual orientation.

Gender Identity (Centers for Disease Control and Prevention)

Question(s)	Response Options	Notes
1. Which of these best describes your current gender identity? Check all that apply.[8]	▪ Male ▪ Female ▪ Transgender man / trans man ▪ Transgender woman / trans woman ▪ Genderqueer/gender nonconforming/non-binary; neither exclusively male nor female[9] ▪ My gender identity is not listed (please specify) ▪ I choose not to answer ▪ I am not sure / don't know	Data collection should start between ages 11 and 13 but should be optional until 16. Data must be collected through patient self-report and health plan/provider staff should never assume a member / patient's gender identity.

[7] The Centers for Disease Control and Prevention's question language of "Do you think of yourself as:" was modified following public comment and MHQP's research.
[8] The Centers for Disease Control and Prevention's question language of "Do you think of yourself as:" was modified following public comment and MHQP's research.
[9] In February 2023, the Taskforce added "non-binary" to this CDC response option in order to be more inclusive.

Sex (Oregon Health Authority)

Question(s)	Response Options	Notes
Sex at Birth: What was your sex assigned at birth?[10]	▪ Male ▪ Female ▪ Intersex ▪ Unspecified ▪ My sex is not listed (please specify) ▪ I choose not to answer ▪ I am not sure / don't know	Data must be collected through patient self-report and health plan/provider staff should never assume a member/patient's sex assigned at birth.

Disability[11] (U.S. Department of Health and Human Services[12])

Question(s)	Response Options	Notes
1. Are you deaf or do you have serious difficulty hearing?	▪ Yes ▪ No ▪ I choose not to answer ▪ I am not sure / don't know	No age threshold.
2. Are you blind or do you have serious difficulty seeing, even when wearing glasses?	▪ Yes ▪ No ▪ I choose not to answer ▪ I am not sure / don't know	No age threshold.
3. Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions?	▪ Yes ▪ No ▪ I choose not to answer ▪ I am not sure / don't know	Question applies to those 5 years or older.

[10] The Oregon Health Authority's question language "When you were born what biological sex was assigned to you?" was modified following MHQP's research.

[11] The Data Standards Advisory Group reluctantly recommended against a separate disability standard specific to children younger than five years old due to the perceived lack of a separate standard that would support efficient and effective identification of disability status for young children 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.

[12] While the Data Standards Advisory Group recommended the Oregon Health Authority standard for disability, which includes three additional questions, the Taskforce ultimately recommended using just the six HHS questions for the time being and gauging a) Oregon's experience with the additional questions, and b) assessments of their validity when the Taskforce data standards are reassessed.

Question(s)	Response Options	Notes
4. Do you have serious difficulty walking or climbing stairs?	▪ Yes ▪ No ▪ I choose not to answer ▪ I am not sure / don't know	Question applies to those 5 years or older.
5. Do you have difficulty dressing or bathing?	▪ Yes ▪ No ▪ I choose not to answer ▪ I am not sure / don't know	Question applies to those 5 years or older.
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 ▪ I choose not to answer ▪ I am not sure / don't know	Question applies to those 15 years or older.

Implementation Considerations

Implementation considerations for the collection of race, ethnicity, and granular ethnicity data include:

- Payer and provider organizations should be able to store multiple values for individuals who identify with multiple races and/or granular ethnicities. Payers and providers will need to determine how to handle these individuals for purposes of analysis.

Implementation considerations for the collection of language data include:

a. Payer and provider organizations should give thought to how to collect language preferences for pediatric and geriatric populations since there may be multiple caregivers with different language preferences.

Implementation considerations for the collection of sexual orientation, gender identity, and sex data include:

a. 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.

Implementation considerations for the collection of disability data include:

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

Implementation considerations for *all* data standards include:

a. Payer and provider organizations should be thoughtful about how to train staff to collect data from members/patients and how to incorporate the data standards into

workflows. Organizations should carefully consider patient privacy when determining mechanisms for data collection.

b. Payer and provider organizations should consider how to best explain to members / patients why organizations are collecting these health equity data. As part of its work, MHQP drafted and tested the following language that may be used for this purpose:
    - "Please tell us about your [race, ethnicity, language preferences, disability status, sexual orientation, gender identity, or sex]. We collect this information to improve the quality of care for everyone we serve. This information is confidential, voluntary, and will never be used to discriminate."
c. Payer and provider organizations should determine at what age children should answer questions on their own, as well as who can answer questions on behalf of young children.
d. Payer and provider organizations should collaborate on facilitating data sharing to avoid unnecessary re-screening of members/patients. Organizations should create their own data hierarchies to determine which data take precedence based on factors such as source, recency, and method of obtainment, among other factors.

Appendix

Health Equity 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)