

Massachusetts Quality Measure Alignment Taskforce

DRAFT Recommended Updates to the Health Equity Data Standards

September 10, 2025

Introduction

The Massachusetts Executive Office of Health and Human Services (EOHHS) convened a new Health Equity Data Standards Technical Advisory Group (Advisory Group) to the Quality Measure Alignment Taskforce (Taskforce) in 2025. The Advisory Group met six times between April and July 2025 to recommend updates to the Taskforce's 2022 standards for the collection of race, ethnicity, language, disability status, sexual orientation, gender identity, and sex. These standards were initially adopted for use by all payers and providers in the Commonwealth. A list of the Advisory Group members can be found in the Appendix.

The Taskforce met on July 29th to review the Advisory Group's recommendations. This document summarizes the Taskforce's final recommendations to EOHHS for changes to the data standards. The Taskforce recommends implementation of these revised standards by January 1, 2028. The recommended changes to the data standards are highlighted below in red font.

The health equity data standards were initially adopted to serve as minimum required standards. Guidance has instructed organizations 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.

Race / Ethnicity (2024 Office of Management and Budget (OMB))

Question(s)	Response Options	Notes
What is your race and/or ethnicity? Check all that apply.	<ul style="list-style-type: none"> ▪ American Indian or Alaska Native ▪ Asian ▪ Black or African American ▪ Hispanic or Latino ▪ Middle Eastern or North African ▪ 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 	<p>1. Maternal race/ethnicity should not automatically be transferred to children.</p> <p>2. For organizations that continue to use the existing 1997 OMB standard (prior to 2028), the standalone Hispanic ethnicity question should ideally be asked before race.</p>

Granular Ethnicity (Massachusetts Department of Public Health; Adapted from 2024 OMB)

Question(s)	Response Options	Notes
What is your ethnicity? Please select the ethnic identity(s) that best describe(s) you. Check all that apply.	<ul style="list-style-type: none"> ▪ African ▪ African American ▪ American ▪ Asian Indian ▪ Brazilian ▪ Cambodian ▪ Cape Verdean ▪ Caribbean Islander ▪ Central American ▪ Chamorro ▪ Chinese ▪ Colombian ▪ Cuban ▪ Dominican ▪ Eastern European ▪ Egyptian ▪ English ▪ European ▪ Fijian ▪ Filipino ▪ French ▪ German ▪ Ghanaian ▪ Guamanian ▪ Guatemalan ▪ Haitian ▪ Honduran ▪ Iranian ▪ Iraqi 	<p>The Massachusetts Superset should be used as constructed; EOHHS may evaluate whether the Superset needs to be updated in the future.</p> <p>1. For <u>data storage</u>, granular ethnicities should be recorded using the existing FHIR categories, be they considered a race or ethnicity by FHIR.</p> <p>2. 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,</p>

	<ul style="list-style-type: none"> ▪ Irish ▪ Italian ▪ Jamaican ▪ Japanese ▪ Korean ▪ Laotian/Lao ▪ Lebanese ▪ Mexican ▪ Middle Eastern or North African ▪ Moroccan ▪ Native Hawaiian ▪ Nigerian ▪ Polish ▪ Portuguese ▪ Puerto Rican ▪ Russian ▪ Salvadoran ▪ Samoan ▪ South American ▪ Syrian ▪ Tongan ▪ Vietnamese ▪ My ethnicity is not listed (please specify) ▪ I choose not to answer ▪ I am not sure / don't know 	these granular ethnicities should each be stored in a customized category.
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Language (American Hospital Association Institute for Diversity and Health Equity; U.S. Census Bureau (2022 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?	<ul style="list-style-type: none"> ▪ English ▪ Spanish ▪ Portuguese ▪ Cape Verdean Creole ▪ Chinese ▪ Haitian Creole ▪ 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 	1. Organizations may decide to separate "Chinese" into "Cantonese," "Mandarin," and "Chinese (Other)" for spoken language. 2. Organizations may decide to separate "Portuguese" into "European Portuguese" and "Brazilian Portuguese" for spoken language.

Written Language: In which language would you feel most comfortable reading medical or health care instructions?	<ul style="list-style-type: none"> ▪ English ▪ Spanish ▪ Portuguese ▪ Chinese (simplified) ▪ Chinese (traditional) ▪ Haitian Creole ▪ French ▪ Vietnamese ▪ Russian ▪ Arabic ▪ I need assistance reading written material ▪ My language is not listed (please specify) ▪ I choose not to answer ▪ I am not sure / don't know 	1. For written language, organizations should <u>not</u> include "Cape Verdean Creole" as a separate option from "Portuguese."
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Disability (U.S. Department of Health and Human Services & Washington Group Short Set)

Question(s)	Response Options	Notes
1. Are you deaf or do you have serious difficulty hearing?	<ul style="list-style-type: none"> ▪ Yes ▪ No ▪ I choose not to answer ▪ I am not sure / don't know 	1. No age threshold.
2. Are you blind or do you have serious difficulty seeing, even when wearing glasses?	<ul style="list-style-type: none"> ▪ Yes ▪ No ▪ I choose not to answer ▪ I am not sure / don't know 	1. No age threshold.
3. Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions?	<ul style="list-style-type: none"> ▪ Yes ▪ No ▪ I choose not to answer ▪ I am not sure / don't know 	1. Question applies to those 5 years or older.
4. Do you have serious difficulty walking or climbing stairs?	<ul style="list-style-type: none"> ▪ Yes ▪ No ▪ I choose not to answer ▪ I am not sure / don't know 	1. Question applies to those 5 years or older.
5. Do you have difficulty dressing or bathing?	<ul style="list-style-type: none"> ▪ Yes ▪ No ▪ I choose not to answer ▪ I am not sure / don't know 	1. Question applies to those 5 years or older.

6. Using your usual language, do you have difficulty communicating, for example understanding or being understood?	<ul style="list-style-type: none"> ▪ Yes ▪ No ▪ I choose not to answer ▪ I am not sure / don't know 	1. Question applies to those 5 years or older.
7. Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping?	<ul style="list-style-type: none"> ▪ Yes ▪ No ▪ I choose not to answer ▪ I am not sure / don't know 	1. Question applies to those 15 years or older.
8. Do you identify as having a disability?	<ul style="list-style-type: none"> ▪ Yes ▪ No ▪ I choose not to answer ▪ I am not sure / don't know 	1. No specified age threshold.

Other disability questions that are excluded from the standards but which organizations may choose to consider for use include:

Question(s)	Response Options	Notes
1. Do you have serious difficulty learning how to do things most people your age can learn?	<ul style="list-style-type: none"> ▪ Yes ▪ No ▪ I choose not to answer ▪ I am not sure / don't know 	<p>1. Question applies to those 5 years or older.</p> <p>2. Question was developed by the Oregon Health Authority and is included in the Massachusetts Department of Public Health disability data standard.</p>
2. Do you have serious difficulty with the following: mood, intense feelings, controlling your behavior, or experiencing delusions or hallucinations?	<ul style="list-style-type: none"> ▪ Yes ▪ No ▪ I choose not to answer ▪ I am not sure / don't know 	<p>1. Question applies to those 15 years or older.</p> <p>2. Question was developed by the Oregon Health Authority and is included in the Massachusetts Department of Public Health disability data standard, with modifications.</p>

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.	<ul style="list-style-type: none">▪ Asexual▪ Straight or heterosexual▪ Lesbian or gay▪ Bisexual▪ Queer▪ Pansexual▪ Questioning▪ My sexual orientation is not listed (please specify)▪ I choose not to answer▪ I am not sure / don't know	<ol style="list-style-type: none">1. Organizations may choose to collect "Lesbian" and "Gay" as separate response options.2. Data collection should start between ages 11 and 13 but should be optional until 16.3. 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
Which of these best describes your current gender identity? Check all that apply.	<ul style="list-style-type: none">▪ Male▪ Female▪ Transgender man / trans man▪ Transgender woman / trans woman▪ Genderqueer/gender nonconforming/non-binary; neither exclusively male nor female▪ My gender identity is not listed (please specify)▪ I choose not to answer▪ I am not sure / don't know	<ol style="list-style-type: none">1. Data collection should start between ages 11 and 13 but should be optional until 16.2. Data must be collected through patient self-report and health plan/provider staff should never assume a member / patient's gender identity.

Sex (Oregon Health Authority)

Question(s)	Response Options	Notes
Sex at Birth: What was your sex assigned at birth?	<ul style="list-style-type: none">▪ Male▪ Female▪ Intersex▪ Unspecified▪ My sex is not listed (please specify)	<ol style="list-style-type: none">1. Data must be collected through patient self-report and health plan/provider staff should never assume a member/patient's sex assigned at birth.

	<ul style="list-style-type: none"> ▪ I choose not to answer ▪ I am not sure / don't know 	
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Implementation Considerations

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

- a. 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 *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:
 - i. "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.

- e. Organizations should consider implementing a mechanism to document when patients, members, or proxies do not have the capacity or ability to respond to the demographic questions during an encounter so that the organization can ensure to ask again at a subsequent encounter, if appropriate.

Appendix

Data Standards Advisory Group Members

- **Katie Acker** (Fallon Health)
- **Madeline Becker** (Seven Hills Foundation)
- **Allison Bryant** (Mass General Brigham)
- **Leonor Fernandez** (Beth Israel Lahey Health)
- **Katelyn Ferreira** (formerly of Southcoast Health)
- **Fili Heider** (Boston Medical Center Health System)
- **Lisa Iezzoni** (Harvard Medical School / Massachusetts General Hospital)
- **Marjorie Janvier** (New England Medical Association)
- **Janice Karin** (Massachusetts Health Data Consortium)
- **Wendy Holt** (DMA Health Strategies)
- **Rita Longe** (Revitalize CDC)
- **Izzy Lopes** (Massachusetts Health and Hospital Association)
- **Natalya Martins** (Massachusetts Health Quality Partners)
- **Adrianna Nava** (National Committee for Quality Assurance)
- **Kevin Nguyen** (Boston University School of Public Health)
- **Lisa Ortendahl** (Beth Israel Lahey Health Performance Network)
- **Kristine Sand** (Blue Cross Blue Shield of Massachusetts)
- **Laura Siller** (Project Bread)
- **Chloe Slocum** (Spaulding Rehabilitation / Harvard Medical School)
- **Kate Staunton Rennie** (Commonwealth Care Alliance)
- **Aswita Tan-McGrory** (Massachusetts General Hospital)