Massachusetts Quality Measure Alignment Taskforce Final Revised Health Equity Data Standards November 17, 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 and again on November 4th to review public comments on the proposed changes. This document summarizes the Taskforce's final, revised data standards approved by the Secretary of Health and Human Services. The Taskforce recommends implementation of these revised standards by January 1, 2028.

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	 American Indian or Alaska Native 	1. Maternal race/ethnicity
and/or ethnicity?	Asian	should not automatically be
Check all that apply.	 Black or African American 	transferred to children.
	Hispanic or Latino	
	 Middle Eastern or North African 	2. For organizations that
	 Native Hawaiian or Other Pacific 	continue to use the existing
	Islander	1997 OMB standard (prior
	White	to 2028), the standalone
	My race is not listed (please specify)	Hispanic ethnicity question
	I choose not to answer	should ideally be asked
	I am not sure / don't know	before race.

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

Question(s)	Response Options	Notes
Please select the ethnic	African American	1. For <u>data storage</u> , granular
identity(s) that best	Asian Indian	ethnicities should be
describe(s) you. Check	Cambodian	recorded using the existing
all that apply.	Cape Verdean	FHIR categories, be they
	Chamorro	considered a race or
	Chinese	ethnicity by FHIR.
	Colombian	
	Dominican	2. Granular ethnicities with no
	Egyptian	determinate OMB
	■ English	classification (Cape
	Fijian	Verdean, Dominican)
	Filipino	should not be mapped to a
	French	minimum OMB category.
	German	Likewise, granular
	Ghanaian	ethnicities that are not
	Guamanian	included in FHIR (Cape
	Guatemalan	Verdean) should not be
	Haitian	mapped to FHIR categories.
	Iranian	Rather, these granular
	Iraqi	ethnicities should each be
	Irish	stored in a customized
	Italian	category.
	Jamaican	
	Japanese	
	Korean	
	Lebanese	
	Mexican	
	Moroccan	
	 Native Hawaiian 	

Nigerian	
Polish	
Puerto Rican	
• Salvadoran	
Samoan	
• Syrian	
Tongan	
Vietnamese	
My ethnicity is not listed (please	
specify)	
I choose not to answer	
I am not sure / don't know	

<u>Language</u> (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:	English	1. Organizations may decide
What language do you	Spanish	to separate "Chinese" into
feel most comfortable	 Portuguese 	"Cantonese," "Mandarin,"
speaking with your	 Cape Verdean Creole 	and "Chinese (Other)" for
doctor or nurse?	Chinese	spoken language.
	 Haitian Creole 	
	 Sign Language, such as ASL 	2. Organizations may decide
	French	to separate "Portuguese"
	Vietnamese	into "European
	Russian	Portuguese" and "Brazilian
	Arabic	Portuguese" for spoken
	 My language is not listed (please 	language.
	specify)	
	I choose not to answer	
	I am not sure / don't know	
Written Language:	English	1. For written language,
In which language	Spanish	organizations should <u>not</u>
would you feel most	Portuguese	include "Cape Verdean
comfortable reading	Chinese (simplified)	Creole" as a separate option
medical or health care	Chinese (traditional)	from "Portuguese."
instructions?	Haitian Creole	
	French	
	Vietnamese	
	Russian	
	Arabic	
	My language is not listed (please	
	specify)	
	I choose not to answer	
	I am not sure / don't know	

<u>Disability</u> (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?	 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?	 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?	 Yes No I choose not to answer I am not sure / don't know 	Question applies to those 5 years or older.
4. Do you have serious difficulty walking or climbing stairs?	 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?	 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?	 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?	 Yes No I choose not to answer I am not sure / don't know 	Question applies to those 15 years or older.
8. Do you identify as having a disability?	 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	Yes	1. Question applies to those 5
difficulty learning how to do	No	years or older.
things most people your age	I choose not to answer	
can learn?	I am not sure / don't know	2. Question was developed by
		the <u>Oregon Health</u>
		Authority and is included
		in the <u>Massachusetts</u>
		Department of Public
		Health disability data
		standard.
2. Do you have serious	Yes	1. Question applies to those 15
difficulty with the following:	No	years or older.
mood, intense feelings,	I choose not to answer	
controlling your behavior, or	I am not sure / don't know	2. Question was developed by
experiencing delusions or		the <u>Oregon Health</u>
hallucinations?		Authority and is included
		in the <u>Massachusetts</u>
		<u>Department of Public</u>
		Health disability data
		standard, with
		modifications.

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.	 Asexual Straight or heterosexual Lesbian or gay Bisexual Queer 	1. Organizations may choose to collect "Lesbian" and "Gay" as separate response options.
	 Pansexual Questioning My sexual orientation is not listed (please specify) I choose not to answer I am not sure / don't know 	2. Data collection may start between ages 11 and 13 but should be optional for organizations to collect until 19.
		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.	 Male Female Transgender man / trans man Transgender woman / trans woman Genderqueer/gender nonconforming/nonbinary; neither exclusively 	 Data collection may start between ages 11 and 13 but should be optional for organizations to collect until 19. Data must be collected through patient self-report and health plan/provider
	 male nor female My gender identity is not listed (please specify) I choose not to answer I am not sure / don't know 	staff should never assume a member / patient's gender identity.

Sex (Oregon Health Authority)

Question(s)	Response Options	Notes
Sex at Birth:	Male	1. Data must be collected
What was your sex assigned at	Female	through patient self-report
birth?	Intersex	and health plan/provider
	My sex is not listed	staff should never assume a
	(please specify)	member/patient's sex
	I choose not to answer	assigned at birth.
	I am not sure / don't	
	know	

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)