

# Appendix A: MassHealth RELD, Sex & SOGI Data Standards \*

\* In this appendix, RELD is used as the abbreviation for race, ethnicity, language & disability status. SOGI is used as the abbreviation for sexual orientation and gender identity.

# **Purpose of this appendix**



The purpose of this appendix is to solicit stakeholder input on potential updates to the internal data standards that MassHealth uses for member-level data regarding race, ethnicity, language, disability status (RELD), sex, sexual orientation and gender identity (SOGI).

- The potential updates detailed within this appendix would primarily impact the application for MassHealth and health plans through the Massachusetts Health Connector, and the data systems used by MassHealth. [1]
- The potential updates detailed within this appendix are not final. Several factors are expected to result in modifications to the information in this appendix, including forthcoming federal guidance on data standards, federal reporting requirements, and input from stakeholders through a public Request for Information (RFI) process.
- Implementing changes to data standards and data systems can take months to years, depending on the scope of the changes.
- MassHealth's internal data standards are **separate** from the standards that organizations, such as ACOs, may follow when reporting data to MassHealth.
- MassHealth collects RELD and sex information for several purposes, including eligibility determination, monitoring of population health, policy development, health equity initiatives, and federal reporting.

#### Footnotes

<sup>[1]</sup> MassHealth is the Medicaid and Children's Health Insurance Program (CHIP) for the state of Massachusetts. The Massachusetts Health Connector is the state-based health insurance exchange for the state of Massachusetts.

# **Ethnicity**



Purpose: This slide describes a possible structure for how MassHealth might collect the data element of ethnicity.

Background:	The paper application for MassHealth and Health Connector health plans asks applicants for their race and ethnicity in a <b>single</b> question (i.e., "what is your race or ethnicity?" on slide 13). [1] The on-line application asks applicants race and ethnicity in <b>separate</b> questions (shown on slide 16).			
Potential Standard:	Option 1: The 2011 HHS Implementation Guidance, with minor modifications described in blue.  Option 2 and 3: CDC Race and Ethnicity Code Set Version 1.0 (March 2000) with a subset of the 43 ethnicities and 900+ races displayed to applicants			
Valid values:  (draft)  Yes, Mexican, Mexican, Chicano/a Yes, Puerto Rican Yes, Cuban Yes, Another Hispanic, Latino/a or Spanish origin Decline to answer [3]  Option 2: What is your ethnicity? (select all that apply).  Valid values existing in MassHealth's data systems content of the CDC Raylo, with a subset of these 900+ values being display choose from. See slide 17 for an example of how this content of the CDC Raylo, with a subset of these 900+ values being display choose from See slide 17 for an example of how this content of the CDC Raylo, with a subset of these 900+ values being display choose from See slide 17 for an example of how this content of the CDC Raylo, with a subset of these 900+ values being display choose from See slide 17 for an example of how this content of the CDC Raylo, with a subset of these 900+ values being display choose from See slide 17 for an example of how this content of the CDC Raylo, with a subset of these 900+ values being display choose from See slide 17 for an example of how this content of the CDC Raylo, with a subset of these 900+ values being display choose from See slide 17 for an example of how this content of the CDC Raylo, with a subset of these 900+ values being display choose from See slide 17 for an example of how this content of the CDC Raylo, with a subset of these 900+ values being display choose from See slide 17 for an example of how this content of the CDC Raylo (select all that apply).		n? (select one) [2], [3]  These 5 values are recommended by the 2011 HHS Implementation Guidance.  They roll-up to the 1997 OMB standard for race & ethnicity that defines two values (i.e., "Hispanic or Latino" and "Not Hispanic or Latino").		
		Valid values existing in MassHealth's data systems could include all of the 43 ethnicities and 900+ races that are part of the CDC Race and Ethnicity Code Set V1.0, with a subset of these 900+ values being displayed for applicants to choose from. See slide 17 for an example of how this option 2 might appear.		
		Valid values could include all ethnicities and races from the <u>CDC Race and Ethnicity Code Set V1.0</u> , with a subset of these values being displayed for		

#### Footnotes:

Additional notes regarding ethnicity are on the next slide

a combined question with checkboxes resulted in increased use of OMB standard categories, and decreased nonresponse. See slide 18 for an

example of how option 3 might appear.

- [1] In Massachusetts, the paper application for MassHealth and Health Connector plans is the Massachusetts Application for Health and Dental Coverage and Help Paying Costs [ACA-3].
- [2] The value of "Unknown" could exist as a valid value in the data, but it would not be displayed as an option for individuals to select. See HL7® Version 3 Null Flavor for types of unknown values.
- [3] The values of "Decline to answer" and "Unknown" are not described in the 1997 OMB minimum standard for race & ethnicity.

# **Ethnicity (continued)**



#### Notes:

- Ethnicity and race currently are not a required fields on the paper and on-line application for MassHealth and Health Connector plans. Applicants are not required to select an ethnicity or race for an application to be considered complete.
- · OMB recommends that ethnicity be asked before race when two separate questions are used for race and ethnicity.
- · Other standards and value sets:
  - o The 1997 OMB standard for race & ethnicity: Federal Register, Federal Register Notice, ONC
  - MA DPH (2009) race, ethnicity & language data standards, and a 2020 version of these standards which has been developed for internal Massachusetts Executive
     Office of Health & Human Services (EOHHS) use.
  - o USCDI V2 ethnicity (July 2021)
  - o CDC Race and Ethnicity Code Set Version 1.0 (2000), which includes 40+ ethnicities and 900+ races: Description. List of races & ethnicities. PHIN VADS ethnicities
  - FHIR v4.01 standards for: race, ethnicity
- Federal reporting: The draft valid values are the same values by which Medicaid programs report ethnicity to CMS, with the exception of the value "Decline to answer".
- Alternative phrasing for asking ethnicity may include the following:
  - o "Are you of Hispanic, Latino, or Spanish origin?" with only "Yes", "No", "Decline to Answer" and "Unknown" as valid values.
  - "Are you of Hispanic, Latinx, or Spanish origin?"
  - o "Are you of Hispanic or Latino origin?".

As per the 1997 OMB standard, the inclusion of "Spanish" is optional. In other words, either "Hispanic or Latino" or "Hispanic, Latino or Spanish" are recommended.

### Race



**Purpose:** This slide describes a possible structure for how MassHealth might collect the data element of **race**.

Background:	The paper application for MassHealth and Health Connector health plans asks applicants for their race and ethnicity in a <b>single</b> question (i.e., "what is your race or ethnicity?" on slide 13). The on-line application asks applicants race and ethnicity in <b>separate</b> questions (shown on slide 16).				
Potential Standard:	Option 1: 1997 OMB minimum standard for race & ethnicity (which has 5 race categories), with minor modifications described in blue.  Option 2 & 3: 2011 HHS Implementation Guidance (which has 14 race categories that roll up to the 5 minimum categories in the OMB standard)				
Questions and Valid values: (draft)	Option 1: What is your race? (select all that apply) [1]  American Indian or Alaska Native  Asian  Black or African American  Native Hawaiian or Other Pacific Islander  White  Other (please specify	Option 2: What is your race? (select all that app  American Indian or Alaska Native Black or African American White Asian Indian Chinese Filipino Japanese Korean Vietnamese Other Asian Native Hawaiian or Other Pacific Islander	These are part of the OMB standard  These roll-up to the Asian category of the OMB standard  These roll-up to the Native		
	data systems could include all of the 43 ethnicities and 900+ races that are part of the CDC Race and Ethnicity Code Set V1.0. For example, an applicant could write-in Portuguese, Haitian, or Chinese in the option for "Other (please specify)."	□ Guamanian or Chamorro □ Samoan □ Other Pacific Islander □ Other (please specify) [2] □ Decline to answer [2]	Hawaiian or Other Pacific Islander category of the OMB standard.		
Option 3: What is your race or ethnicity? (select all that apply). See slide 18 for an example of how option 3 m			might appear.		

#### Notes:

- As recommended by 1997 OMB guidelines, "multi-racial" is not a category. Instead, individuals can select all race categories that apply.
- An alternative to displaying "American Indian or Alaska Native" is to provide an additional option to write-in a tribal nation, using the following option: "American Indian or Alaska Native (specific tribal nation: \_\_\_\_\_\_\_)". U.S. Census Bureau research found that a write-in option increased detailed reporting for this group, when compared to three checkboxes (for American Indian, Alaska Native, and Central/South American Indian) and a write-in option.
- Other standards and value sets considered:
  - o MA DPH (2009) race, ethnicity & language data standards, and a 2020 version of these standards which has been developed for internal Massachusetts EOHHS use.
  - o USCDI V2 race (July 2021)
  - o 2011 HHS Implementation Guidance which describes 14 different races, that roll-up to the 5 races that are specified in the 1997 OMB race and ethnicity standard.
  - CDC Race and Ethnicity Code Set Version 1.0 (March 2000), which includes ~900 races: Description. List of ethnicities. PHIN VADS
- Federal reporting: The proposed valid values are the same values by which Medicaid programs report race to CMS (with the exception of "Decline to answer" and "Other (please specify)".

#### Footnotes:

[1] The value of "Unknown" could exist as a valid value in the data, but it would not be displayed as an option for individuals to select. See HL7® Version 3 Null Flavor for types of unknown values.

# Language



**Purpose:** This slide describes a possible structure for how MassHealth might collect the data element of **language**.

Background:	<ul> <li>The paper and on-line applications ask for "preferred spoken language" and "preferred written language".</li> <li>"Preferred written language" is used by MassHealth to determine what language is used for written notices that are sent via mail to individuals.</li> <li>English proficiency is not currently asked in the paper or electronic application.</li> <li>There is not yet a widely adopted national standard for preferred language. [1]</li> </ul>				
Potential	2011 HHS Implementation Guidance (which recommends English proficiency as the single question regarding language)				
Standard:	• ISO 639-2 (which specifies a code list that includes 487 languages; The Library of Congress is the ISO 639-2 Registration Authority)				
	Using all three of the following questions is proposed:				
	1. Spoken language: What language do you prefer when speaking about health? (select one if 5 years old or older) [2], [3]				
Questions	□ American Sign Language □ French □ Mandarin (Chinese) □ Other (specify)				
and	□ Arabic □ German □ Portuguese □ Decline to answer □ Cantonese (Chinese) □ Haitian Creole □ Spanish				
Valid values:	□ <b>English</b> □ Hindi □ Vietnamese				
(draft)	2. Written language: In what language do you prefer health-related written materials? (select one) [2], [3]				
	□ Arabic □ French □ Mandarin (Chinese) □ Other (specify) □ Braille / Large Print □ German □ Portuguese □ Decline to answer □ Cantonese (Chinese) □ Haitian Creole □ Spanish □ English □ Hindi □ Vietnamese				
	The information regarding "preferred written language" may be used to help MassHealth and the Health Connector communicate with applicants and members. Written notices currently are produced in English and Spanish.  While providing language preferences is optional, it is strongly encouraged. If a member/applicant declines to provide this information, then the "decline in the information is a member of the information in the information is a member of the information in the information is a member of the information in the information is a member of the information in the information is a member of the information in the information is a member of the information in the information is a member of the information in the information is a member of the information in the information is a member of the information in the information is a member of the information in the information is a member of the information in the information is a member of the information in the information is a member of the information in the information is a member of the information in the information is a member of the information in the information in the information in the information is a member of the information in the information i				
	to answer" option should be selected. If no selection is made, then the member/applicant's preferred language will be recorded as "unknown".				
	3. English proficiency: How well do you speak English? (select one if 5 years old or older) [3]  Very well  Well  Well				
	□ Not well □ Not at all □ Decline to answer				
Footnotes:	Additional notes regarding language  are on the next slide ————————————————————————————————————				

[3] The value of "Unknown" could exist as a valid value in the data, but it would not be displayed as an option for individuals to select. See HL7® Version 3 Null Flavor for types of unknown values.

<sup>[1]</sup> Source: ONC's webpage on Representing Patient Preferred Language.
[2] Valid values for language are listed alphabetically, except Other and Decline to answer are listed last. Which languages to display can be determined using different methodologies, for example displaying the top 10 or 20 most common languages spoken in MA according the American Community Survey. The exact number of languages that are displayed to applicants may depend on space available on the paper & electronic applications. There are different methods for determining the order in which languages are displayed, including: (a) alphabetically; (b) in order of decreasing frequency in the state; (c) by groups, whereby dialects of Chinese are grouped together, and dialects of Portuguese are grouped together.

# Language (continued)



#### Notes:

 Applicants have the option of not selecting any of the options regarding language displayed on an application. Not providing any information about language results in that individual receiving notices in English language.

#### Other standards and value sets:

- The <u>USCDI V2 (July 2021)</u> includes "preferred language" but not English proficiency, written language or spoken language.
   The USCDI V2 does not have a standard yet for preferred language.
- o FHIR v4.01 standards for: race, ethnicity, disability status, written language, languages, language ability mode

#### · Alternative questions and phrasing to consider:

- o Remove American Sign Language as one of the valid values displayed under the question, "What language do you prefer when speaking about health?"
- o Instead of using the phrase, "What language do you prefer to speak in about health?" use one of the alternatives:
  - "What language do you prefer to communicate in about health?"
  - "What is your preferred spoken language"
  - "What is your preferred language"
  - "Do you speak a language other than English at home? If "yes", then what is this language?"
     This option is recommended by the 2011 HHS Implementation Guidance for organizations that want additional information above English proficiency.
- Federal reporting: Medicaid programs are required to report primary language to CMS using the set of <a href="ISO 639-2">ISO 639 is a set of international standards that provides short codes for over 400 languages.</a>
- The question regarding English proficiency (i.e., question #3 on the previous slide) is the recommended standard as per the 2011 HHS Implementation Guidance. It is based on the language question in the American Community Survey (ACS), and in the 2000 and 2010 Census.

# **Disability status**



**Purpose:** This slide describes a possible structure for how MassHealth might collect information related to **disability status**.

Background:	There is not yet a widely adopted national standard for disability status or disability. [1]		
Potential Standard:	To be determined		
	The two questions below are currently used in the paper and electronic applications:		
Questions	<ul> <li>Do you have an injury, illness, or disability (including a disabling mental condition) that has lasted or is expected to last for at least 12 months? If legally blind, answer Yes. [2]</li> </ul>		
and  Valid values:	□ Yes <sup>[4]</sup> □ No		
(draft)	<ul> <li>Do you need reasonable accommodation because of a disability or an injury?</li> <li>If Yes, complete the rest of this application, including Supplement C: Accommodation. [2], [3]</li> <li>Yes</li> <li>No</li> </ul>		

#### Notes:

- · Other standards and value sets considered:
  - 2011 HHS Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language and Disability Status: For population surveys, HHS recommends the following six standardized questions regarding disability status. These questions are used by population surveys from HHS (e.g., BRFSS, MEPS), U.S. Census Bureau (e.g., ACS), etc.
    - 1. Are you **deaf** or do you have serious difficulty hearing?
    - 2. Are you **blind** or do you have serious difficulty seeing, even when wearing glasses?
    - 3. Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions?
    - 4. Do you have serious difficulty walking or climbing stairs?
    - 5. Do you have difficulty dressing or bathing?
    - 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?

While these six questions are currently used in population-based health surveys, information collected by the current MassHealth application regarding disabilities and reasonable accommodations are used for individual-level eligibility determination and need for services.

- USCDI V2 (July 2021) does not include a definition or standard for disability status
- Federal reporting: Medicaid programs are required to report "disability type" to CMS using valid values corresponding to the 6 disability-related questions listed above from 2011 HHS Guidance

#### Footnotes:

- [1] Source: ONC's webpage on Representing Functional Status and/or Disability Status
- [2] The value of "Unknown" could exist as a valid value in the data, but it would not be displayed as an option for individuals to select. See HL7® Version 3 Null Flavor for types of unknown values.
- [3] Supplement C is shown on slide 20.
- [4] If an applicant answers "yes" to this question regarding injury, illness or disability lasting at least 12 months, and that applicant is not verified as being disabled according to an electronic data matching process with the federal Social Security Administration or the Massachusetts Rehabilitation Commission, then the applicant is asked to complete an Adult Disability Supplement (slide 21).

# Sex



**Purpose:** This slide describes one possible data structure for the data element of **sex.** 

Background:	The paper and online applications for MassHealth and Health Connector health plans ask applicants for sex, with "Male" or "Female" being the only options.		
Potential Standard:	USCDI V2 standard regarding "Sex (Assigned at Birth)" (July 2021) with minor modifications described in blue.		
Questions	What sex were you assigned at birth? * [1]  □ Male □ Female □ Other (specify)		
Valid values: (draft)	* An asterisk indicates a required field		

#### Notes:

- Other standards and value sets considered:
  - o HL7 Version 3 Value Set (for "Administrative Gender"). The HL7 V3 value set included the value of "Undifferentiated" which is proposed to not be included as a valid value.
  - o FHIR v4.01 standards for: administrative gender, gender identity
  - ONC web page regarding <u>Representing Patient Sex (At Birth)</u>
  - MA DPH draft SOGI data guidelines, which have been developed for internal EOHHS use.
- Different standards exist for sex assigned at birth, administrative gender, gender for clinical purposes, and biologic sex.
- Federal reporting:
  - o Medicaid programs are required to report sex to CMS using the valid values of "Male", "Female" and "Unknown"
  - CMS technical specifications describe that the sex data element corresponds to an individual's biologic sex.
- Alternative questions or phrasing for this data element may include the following:
  - o "What is your sex?" or "What is your biologic sex?" or ...
  - "What is your biological sex or your self-identified sex?" (This phrasing is referenced in the definition for sex in the T-MSIS Data Dictionary v2.4.0, from December 2020).
- Additional or alternative valid values to consider:
  - o "Undetermined" (this potential value his could be considered since it is a valid value for birth certificates in Massachusetts)
  - "Intersex"
- Background information regarding birth certificates in Massachusetts:
  - o The state-wide electronic birth registration system has the following valid values for sex: Male, Female, Undetermined.
  - o "Undetermined" is used only in cases of intersex or extreme prematurity where the sex was not able to be determined.
  - o A birth record can be amended based on gender affirming surgery, with choices being Male or Female.

#### Footnotes:

[1] The value of "Unknown" could exist as a valid value in the data, but it would not be displayed as an option for individuals to select. See HL7® Version 3 Null Flavor for types of unknown values.

# Sexual orientation & Gender identity (SOGI)



Purpose: This slide describes a possible structure for how MassHealth might collect the data elements of sexual orientation and gender identity.

Background:	The paper and online applications for MassHealth and Health Connector health plans do not ask applicants their sexual orientation or gender identity.		
Potential Standard:	USCDI V2 standards related to Gender Identity and Sexual Orientation with minor modifications described in blue.		
Questions and Valid values: (draft)	<ul> <li>□ Gay or lesbian</li> <li>□ Straight or heterosexual</li> <li>□ Queer</li> <li>□ Do not know</li> <li>□ Other, specify:</li> </ul>	Something else, please describe	
	<ul> <li>□ Decline to answer</li> <li>What is your gender? (select one) [1], [2]</li> <li>Answer this question if age 18 or above. [3]</li> <li>□ Male</li> <li>□ Female</li> <li>□ Nonbinary, genderqueer, or not exclusively male or female</li> <li>□ Other, specify:</li> <li>□ Decline to answer</li> </ul> Are you transgender? (select one) [1], [4] Answer this question if age 18 or above. [3] <ul> <li>□ Yes</li> <li>□ No</li> <li>□ Do not know</li> <li>□ Decline to answer</li> </ul>	Genderqueer, neither exclusively male nor female Additional gender category or other, please specify Choose not to disclose	

#### Footnotes:

- [1] The value of "Unknown" could exist as a valid value in the data, but it would not be displayed as an option for individuals to select. See HL7® Version 3 Null Flavor for types of unknown values.
- [2] Alternative phrasing of this question to consider: "What is your gender identity?"
- [3] Alternative to consider: an age other than 18 could be used. MA General Laws Chapter 231, section 85P recognizes 18 as the age when state residents are legally considered an adult.
- [4] Alternative to consider: Instead of having "Are you transgender?" as a separate question, include "Transgender Male" and "Transgender Female" as options (alongside Male, Female and Non-binary) within a single question regarding, "What is your gender identity?

# **SOGI** (continued)



### Notes:

- Other standards and value sets considered:
  - o MA DPH draft SOGI data guidelines, which have been developed for internal EOHHS use.
  - o UCSF Guidelines (June 2016)
  - o ONC web pages regarding Gender Identity and Sexual Orientation
- Additional background information:
  - Massachusetts:
    - "Gender X" is an option on state driver licenses.
    - Massachusetts state laws regarding gender identity or expression
  - Federal:
    - The U.S. State Department plans to add a "gender marker for non-binary, intersex, and gender non-conforming persons" when applying for a passport. (June 2021 release)



Supplemental information

# Race and Ethnicity: Current state



### Paper application: [1]

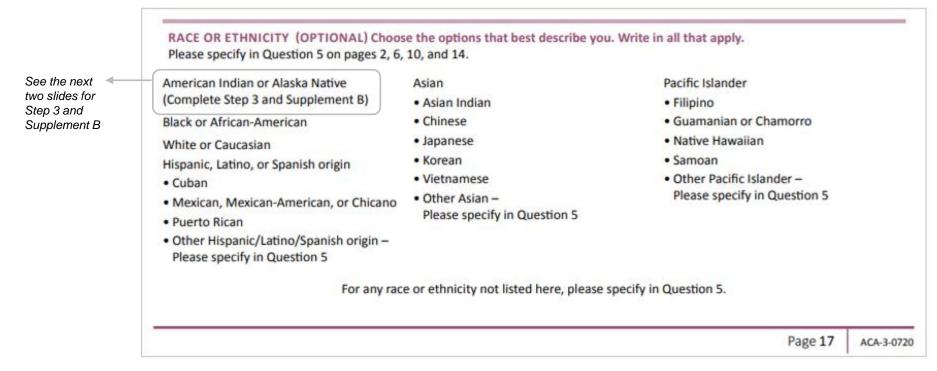
The question below regarding race or ethnicity is on **page 6** of the paper application:

5. Optional What is your race or ethnicity? \_\_\_\_\_\_ Please see page 17.

MassHealth is committed to providing equitable care for all members regardless of race, ethnicity, or language spoken.

Please complete this question to help us meet your language and cultural needs. Know that your response is voluntary, confidential, and will not impact your eligibility or be used for any discriminatory purpose.

The race or ethnicity options listed below appear on **page 17** of the paper application:



#### Notes:

<sup>[1]</sup> The paper application (which is formally titled the Massachusetts Application for Health and Dental Coverage and Help Paying Costs [ACA-3]) is available here.

# Race and Ethnicity: Current state (continued)



# Paper application:

Step 3 (shown below) is on page 18 of the paper application.

STEP 3 American Indian or Alaska Native (AI/AN) Household Member(s)			
1. Are you or is anyone in your household an American Indian or Alaska Native? Yes No			
If No, skip to Step 4.			
If Yes, complete the rest of this application, including Supplement B: American Indian or Alaska Native Household Member.			
Names(s) of person(s)			
American Indians and Alaska Natives who enroll in health coverage can also get services from the Indian Health Service, tribal health programs, or Urban Indian Health Programs. If you or any household members are American Indians or Alaska Natives, you may not have to pay premiums or copayments, and may get special monthly enrollment periods.			

# Race and Ethnicity: Current state (continued)

**Paper application:** Supplement B is **page 23** of the paper application.



### American Indian or Alaska Native SUPPLEMENT (B) Household Me Complete this supplement if you or a household member are an A TELL US ABOUT YOUR AMERICAN INDIAN OR ALAS American Indians and Alaska Natives can get services from the Ind programs. They also may not have to pay premiums or copayment following questions to make sure your household gets the most he NOTE: If you have more people to include, make a copy of this pay AI/AN PERSON 1 1. Name (first, middle, last) 2. Member of a federally recognized tribe? Yes No If Yes, tribe name 3. Member of a Massachusetts-recognized tribe? Yes No If Yes, tribe name 4. Has this person ever gotten a service from the Indian Health Service, a tribal health program, or Urban Indian Health Program, or through a referral from one of these programs? Yes No If No, is this person eligible to get services from the Indian Health Service, tribal health programs, or Urban Indian Health Program, or through a referral from one of these programs? Yes No 5. Certain money received may not be counted for MassHealth. List any income (amount and how often) reported on your application that includes money from · Per capita payments from a tribe that come from natural resources, usage rights, leases, or royalties; · Payments from natural resources, farming, ranching, fishing, leases, or royalties from land designated as Indian trust land by the Department of the Interior (including reservations and former reservations); or · Money from selling things that have cultural significance.

— How often? —

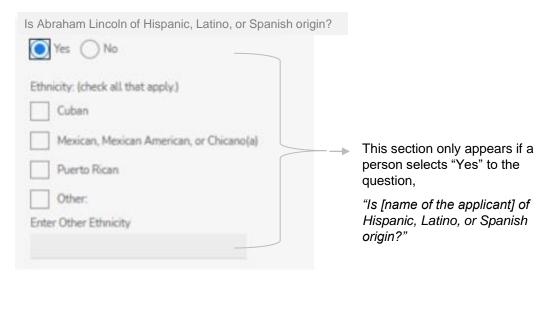
mber (AI/AN)					
KA Na lian Hea is and re elp pos	n Indian or Alaska Native.  ATIVE HOUSEHOLD MEMBER(S).  alth Service, tribal health programs, or urban Indian health nay get special monthly enrollment periods. Answer the sible.  attach it.				
AI/	AI/AN PERSON 2				
1.	Name (first, middle, last)				
2.	Member of a federally recognized tribe?  Yes No				
3.	Member of a Massachusetts-recognized tribe?  Yes No  If Yes, tribe name				
4.					
If No, is this person eligible to get services from the Indian Health Service, tribal health programs, or Urban Indian Health Program, or through a referral from one of these programs?  Yes No					
5.	Certain money received may not be counted for MassHealth. List any income (amount and how often) reported on your application that includes money from				
	Per capita payments from a tribe that come from natural resources, usage rights, leases, or royalties; Payments from natural resources, farming, ranching, fishing, leases, or royalties from land designated as Indian trust land by the Department of the Interior (including reservations and former reservations); or				
	Money from selling things that have cultural significance.  S How often?				

# Race and Ethnicity: Current state (continued)



Electronic application: [1]

### Part 1: Ethnicity



### Part 2: Ethnicity

Race: (check all that apply.)
American Indian or Alaska Native
Asian Indian
Black or African American
Chinese
Filipino
Guamanian or Chamorro
Japanese
Korean
Native Hawaiian
Other Asian
Other Pacific Islander
Samoan
Vietnamese
White or Caucasian
Other:
Enter other race

### Footnotes:

<sup>[1]</sup> The online application is available <a href="here">here</a> (on mass.gov) and <a href="here">here</a> (on the Massachusetts Health Connector website).

# **Ethnicity: displaying a detailed list**



**Purpose:** This slide describes one option for collecting ethnicity, where a detailed list of ethnicities is displayed to an applicant. In this option, the list of ethnicities is very different than the minimum OMB standard where the only two ethnicities are Hispanic/Latino, or not Hispanic/Latino.

what is your ethnicity? (select all that apply) 🖽				
□ African (specify country)	□ Haitian	□ Other (specify)		
□ African American	□ Honduran	□ Decline to answer		
□ Albanian	□ Indian /Asian Indian (from/family from India)*			
□ American	□ Irish			
□ Armenian	□ Italian			
□ Brazilian	□ Japanese			
□ Cambodian/Khmer	□ Korean			
□ Canadian	□ Laotian			
□ Cape Verdean	□ Mexican, Mexican American, Chicano			
□ Caribbean Islander (specify)	□ Middle Eastern (specify)			
□ Chinese	□ Native American			
□ Colombian	□ Polish			
□ Cuban	□ Portuguese			
□ Dominican	□ Puerto Rican			
□ English	□ Russian			
□ Filipino	□ Salvadoran			
□ French	□ Scottish			
□ German	□ Swedish			
□ Greek	□ Ukrainian			
□ Guatemalan	□ Vietnamese			

#### Footnotes:

[1] The value of "Unknown" could exist as a valid value in the data, but it would not be displayed as an option for individuals to select. See HL7® Version 3 Null Flavor for types of unknown values.

#### Notes:

- In the option for collecting ethnicity which is provided on this slide, the list of ethnicities that are displayed could be determined by different methods including using recommendations from MA DPH and/or the most prevalent ethnicities in Massachusetts according to data from the American Community Survey.
- The options displayed on this slide are adapted from the MA DPH (2009) race, ethnicity & language data standards,

# **Race and Ethnicity Single-Question Format**



Purpose: This slide provides an example of asking race and ethnicity in a single-question format, instead of as two separate questions.

8. WI	nat is Person 1's race or ethnicity?  It al boxes that apply AND print ethnicities in the spaces below.  It you may report more than one group.  WHITE – Provide details below.  German   Irish   English   Italian   Polish   French  Print, for example, Scottish, Norwegian, Dutch, etc.  HISPANIC, LATINO, OR SPANISH – Provide details below.  Mexican or Mexican   Puerto   Cuban American	AMERICAN INDIAN OR ALASKA NATIVE - Print, for example, Navajo Nation, Blackfeet Tribe, Mayan, Aztec, Native Village of Barrow Inupiat Traditional Government, Tlingit, etc.  MIDDLE EASTERN OR NORTH AFRICAN - Provide details below.  Lebanese   Iranian   Egyptian   Syrian   Moroccan   Algerian   Print, for example, Israeli, Israeli, Tunisian, etc.  NATIVE HAWAIIAN OR OTHER PACIFIC ISLANDER - Provide	<ol> <li>Possible modifications to the example on this slide could include the following:</li> <li>Remove the instructions to "print ethnicities in the spaces below" so that the instructions say, "Mark all boxes tha apply."</li> <li>Remove the first 6 write-in fields leaving only the last write-in field for "some other race or ethnicity."</li> <li>Add a value for "decline to answer."</li> </ol>
	Salvadoran Dominican Colombian  Print, for example, Guatemalan, Spaniard, Ecuadorian, etc.  BLACK OR AFRICAN AMERICAN – Provide details below.  African Jamaican Haitian Nigerian Ethiopian Somali  Print, for example, Ghanaian, South African, Barbadian, etc.  ASIAN – Provide details below.	details below.    Native	<ul> <li>Examples of how an applicant may respond to this single-question format:</li> <li>1. A person who views themselves as Asian-American:  This person might select "Asian".  Or they might write "Asian American" in the field for "Some other race or ethnicity".</li> <li>2. A person who has one parent that identifies themselves as African</li> </ul>
Intes	☐ Chinese ☐ Filipino ☐ Asian Indian ☐ Vietnamese ☐ Korean ☐ Japanese Print, for example, Pakistani, Cambodian, Hmong, etc.		American, and one parent that identifies as White with European ancestors:  This person may select "White" and "Irish" and "Black or African American".  Or they might write "biracial" in the field for "Some other race or ethnicity".

- The above example is described in two sources:
  - o 2015 National Content Test: Race and Ethnicity Analysis Report. U.S. Census Bureau. 2017 (page 88). This report found that "the optimal question format is combined question with detailed checkboxes" (page xii).
  - Collection of REL Data in Medicaid Applications: A 50-state Review of the Current Landscape. State Health Access Data Assistance Center. May 2021 (page 4). This report describes that 6 out of 50 state Medicaid programs use a combine race/ethnicity question, while 46 use separate questions for race and ethnicity.

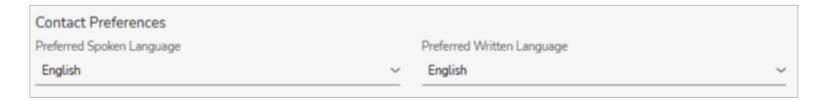
# **Language: Current state**



### Paper application:

19. What is your preferred language, if not English? Spoken	Written	
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### **Electronic application:**



The drop-down menus for Preferred Spoken Language and Preferred Written Language include the following 23 options:

- English
- Arabic
- · Cambodian / Khmer
- Cape Verdean Creole
- Chinese Cantonese
- Chinese Mandarin
- French
- Greek
- Gujarati

- · Haitian Creole
- Hindi
- Italian
- Korean
- Laotian
- Nepalese
- Polish
- Portuguese Brazilian
- Portuguese European

- Russian
- Somali
- Spanish
- Vietnamese
- Other

# **Disability:** Current state



# Paper application:

13	Do you have an injury, illness, or disability (including a disabling mental health condition) that has lasted or is expected to last for at least 12 months? If legally blind, answer <b>Yes</b> . Yes No			
14	<ol> <li>Do you need reasonable accommodation because of a disability or an injury?</li></ol>			
	SUPPLEMENT ( HEALTH CONNECTOR			
	If you answered Yes to Question 14 in Step 2 about yourself or any household member needing reasonable accommodation because of a disability or injury, check all that apply below, and list name(s).			
	1. Condition  Blind—Name(s):			
	☐ Deaf—Name(s):			
l	Developmentally disabled—Name(s):			
	Hard of hearing—Name(s):			
	Intellectually disabled—Name(s):			
	Low vision—Name(s):			
	Physically disabled—Name(s):			
	Other (Please explain.)—Name(s):			
١.	2. Accommodation			
	American Sign Language (ASL) interpreter—Name(s):			
	Assistive listening device—Name(s):			
	Communication Access Real-time Translations (CART)—Name(s):			
	Large print publications—Name(s):			
	Publications in braille—Name(s):			
	Publications in electronic format—Name(s):			
	Text telephone (TTY)—Name(s):			
	☐ Video Relay Service (VRS)—Name(s):			
	Other (Please explain.)—Name(s):			

# **Disability:** Current state (continued)



# MassHealth **Adult Disability Supplement**





Commonwealth of Massachusetts | Executive Office of Health and Human Services

### Instructions for Completing the Supplement

You have indicated on your MassHealth application that you have a disability. Disability standards require that the disability has lasted or is expected to last at least 12 months. UMass Disability Evaluation Services (DES) will review your disability application for MassHealth. It is very important that you complete this Disability Supplement.

To get MassHealth based on your disability, you need to tell us about

- your medical and mental health providers. These may include doctors, psychologists, therapists, social workers, physical therapists, chiropractors, hospitals, health centers, and clinics from whom you receive or have received treatment; and
- yourself: your work history for the past 15 years, your educational background, and your daily activities.

#### Completing the Disability Supplement will give us this information and will help us make a quick decision.

Please read the following instructions before beginning.

- Print, or write clearly and complete the supplement to the best of your ability.
- Sign and date an Authorization to Release Protected Health Information Form for each medical and mental health provider you list on the supplement.
- · After you have filled out the supplement, submit it to Disability Evaluation Services / UMASS Medical DES P.O. Box 2796 Worcester, MA 01613-2796

DES will ask for your medical and treatment records from the providers you have listed. If you have any of your medical records, please send a copy with this form. If more information or tests are needed, a member of DES will get in touch with you. Your eligibility will be determined more quickly if all items on the supplement are filled in.

This is not an application for medical benefits. If you have not already completed a MassHealth application, you must fill one out in addition to this form. If you have any questions about how to apply, please call (800) 841-2900 (TTY: (800) 497-4648 for people who are deaf, hard of hearing, or speech disabled).

If you need help with this form, you can call the UMass Disability Evaluation Services (DES) Help Line at (888) 497-9890. Fill in every section of this form. If you do not fill in every section, we may not be able to decide if you are disabled.

Informati	on about yo	ou Male	Female	
Last name	First name	Middle initial		Social security number

#### Notes:

- If an applicant answers "yes" to the question on the previous slide regarding injury, illness or disability lasting at least 12 months, and that applicant is not verified as being disabled according to an electronic data matching process with the federal Social Security Administration or the Massachusetts Rehabilitation Commission, then the applicant is asked to complete the Adult Disability Supplement.
- The Adult Disability Supplement (16 pages) is available on the webpage for MassHealth Member Forms.

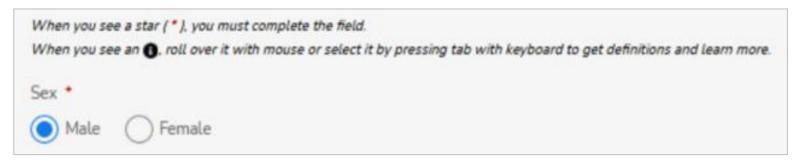
# **Sex:** Current state



### Paper application:

2. Relationship to you <b>SELF</b>	3. Date of birth (mm/dd/yyyy)	4. Gender Male Female

# **Electronic application:**



# Resources

### Massachusetts:



- Medicaid paper application: i.e., Massachusetts Application for Health and Dental Coverage and Help Paying Costs [ACA-3]
- Medicaid online application: available <a href="here">here</a> (on mass.gov) and <a href="here">here</a> (on the Massachusetts Health Connector website
- MA DPH (2009) race, ethnicity & language data standards, and a 2020 version of these standards which has been developed for internal Massachusetts Executive Office of Health & Human Services (EOHHS) use.

### National:

- 1977 Office of Management and Budget (OMB) race and ethnicity standards
- 1997 Office of Management and Budget (OMB) race and ethnicity standard
- 2011 HHS Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status
- T-MSIS Data Dictionary
- FHIR v4.01 standards for: race, ethnicity, disability status, written language, languages, language ability mode, administrative gender, gender identity
- United States Core Data for Interoperability (USCDI):
  - o <u>USCDI V2</u> (released July 2021)
- CDC Race and Ethnicity Code Set Version 1.0 (March 2000)
  - Overview from CDC (6 pages)
  - o Table 1 and 2 (i.e., the list of races and ethnicities) (38 pages); CDC Code set as detailed in CDC's PHIN VADS
- ONC standards for the following data elements:
  - Race and Ethnicity
  - o Preferred Language
  - o Functional Status and/or Disability
  - o Sex (At Birth)
  - o Sexual Orientation
  - o Gender Identity
- HL7 V3 Null Flavor (i.e., different types of "Unknown" values):
  - o As specified by CDC's Public Health Information Network Vocabulary Access and Distribution System (PHIN VADS)
  - o As specified by HL7 V3
- Collection of REL Data in Medicaid Applications: A 50-state Review of the Current Landscape. State Health Access Data Assistance Center (2021)