CMS OMH Recommendations on US Core Data for Interoperability (USCDI) standards

Date: July 09, 2021
To: National Coordinator for Health Information Technology, ONC
From: CMS OMH Office of Minority Health

CMS Office of Minority Health (OMH) would like to provide feedback on the proposed US Core Data for Interoperability (USCDI) standards V2 Draft, as outlined below.

Executive Order 13985, issued on January of 2021, states that "the Federal Government should pursue a comprehensive approach to advancing equity for all, including people of color and others who have been historically underserved, marginalized, and adversely affected by persistent poverty and inequality". It calls upon agencies to identify and work to redress inequities in their policies and programs that create barriers to equal opportunity to ensure that everyone can reach their highest potential.

Although health disparities are not new, the COVID-19 pandemic has exposed how the gaps in our data collection and understanding of individuals' social risk factors can prevent us from protecting our most vulnerable beneficiaries and ultimately lead to lives lost. It is critically important that we improve our understanding of beneficiaries' social risk factors, so that under normal circumstances – and especially in crisis – we are able to save lives, protect health, and ensure our beneficiaries get the right care, in the right place, at the right time.

The information below reflects CMS OMH's feedback to ONC for modifications to the USCDI standards, to improve and enhance data collection and interoperability efforts.

Section 4302 of the Affordable Care Act (ACA) requires the Secretary of DHHS to establish data collection standards for race, ethnicity, sex, primary language, and disability status. The law requires that, once established, these data collection standards be used, to the extent practicable, in all national population health surveys. In response to this statutory requirement, ASPE published implementation guidance on October 31, 2011, which outlines the new minimum data collection standards for race, ethnicity, sex, primary language, and disability status for implementation in HHS, along with a description of the data standards development process, the rationale for each data standard, and instructions for their implementation.

Section A: Existing Standards

The following section details feedback on standards present in the V2 draft.

Race

The CMS Office of Minority Health (OMH) recommends that the proposed US Core Data for Interoperability (USCDI) standards V2 Draft align with the 2011 race standards, as outlined below.

HHS 2011 Data Standard:
What is your race?
(One or more categories may be selected)

a. ____*White*
b. ____*Black or African American*
c. ____*American Indian or Alaska Native*

The above categories are part of the OMB standard

d. ___*Asian Indian*
e. ___*Chinese*
f. ___*Filipino*
g. ___*Japanese*
h. ___*Korean*
i. ___*Vietnamese*
j. ___*Other Asian*

The above categories roll-up to the Asian category of the OMB standard

k. ___*Native Hawaiian*
l. ___*Guamanian or Chamorro*
m. ___*Samoan*
n. ___*Other Pacific Islander*

The above categories roll-up to the Native Hawaiian or Other Pacific Islander category of the OMB standard

Justification

- Section 4302 of the Affordable Care Act, required HHS to develop uniform data collection standards.
- The race data elements of the CDC standard can roll up to the HHS 2011 race categories and the data elements of both the HHS 2011 and CDC standards can also roll up to the OMB standard categories, therefore HHS 2011 data standard should be the minimum required standard rather than the 1997 OMB standard. This would allow for greater granularity when reporting race, while still adhering to the OMB standard. This granularity is critical for stratifying data and identifying disparities in population health, healthcare access and health outcomes.

- This standard will help to align with existing Federal data collection instruments and increases CMS' ability to analyze health disparities in Medicare, which is critically necessary for quality improvement and responsiveness to public health emergencies such as COVID-19.
- The 2011 HHS race standard is being implemented across several CMS programs like HHA, SNF, LTCH, IRF, and Hospice.

Ethnicity

The CMS Office of Minority Health (OMH) recommends that the proposed US Core Data for Interoperability (USCDI) standards V2 Draft align with the 2011 ethnicity standards, as outlined below.

HHS 2011 Data Standard:

Are you Hispanic, Latino/a, or Spanish origin
(One or more categories may be selected)

a. ____*No, not of Hispanic, Latino/a, or Spanish origin*
b. ____*Yes, Mexican, Mexican American, Chicano/a*
c. ____*Yes, Puerto Rican*
d. ____*Yes, Cuban*
e. ____*Yes, another Hispanic, Latino, or Spanish origin*

These categories roll-up to the Hispanic or Latino category of the OMB standard

Justification

- Section 4302 of the Affordable Care Act, required HHS to develop uniform data collection standards.
- The ethnicity data elements of the CDC standard can roll up to the HHS 2011 ethnicity categories and the data elements of both the HHS 2011 and CDC standards can also roll up to the OMB standard categories, therefore HHS 2011 data standard should be the minimum required standard rather than the 1997 OMB standard. This would allow for greater granularity when reporting ethnicity, while still adhering to the OMB standard. This granularity is critical for stratifying data and identifying disparities in population health, healthcare access and health outcomes.
- This standard will help to align with existing Federal data collection instruments and increases CMS' ability to analyze health disparities in Medicare, which is critically necessary for quality improvement and responsiveness to public health emergencies such as COVID-19.
- The 2011 HHS ethnicity standard is being implemented across several CMS programs like HHA, SNF, LTCH, IRF, and Hospice.

Preferred Language

Given the access issues related to macrolanguages, a group of individual languages which are closely related to each other and are considered as a single language in certain contexts, the coding operations used by the US Census Bureau put the reported answers from the preferred language question "What is this language?" into language categories. In 2016, the code list was revised to match the International would allow entities to determine how and where to provide language assistance service. Knowing languages spoken in a community, in combination with other variables, helps the government and communities identify needs for services for people with limited English-speaking ability. Examples of Macrolanguages include Arabic and Chinese.

CMS OMH believes this is important, as Section 4302 of the Affordable Care Act requires HHS to develop uniform data collection standards.

Hence, CMS OMH recommends the following preferred language question and response options.

“What is your preferred language?” If the patient is unable to respond, ask the caregiver:

A. English
B. Spanish
C. Amharic
D. Arabic
    a. North Levantine Arabic
    b. Egyptian Arabic
    c. South Levantine Arabic
    d. Mesopotamian Arabic
    e. Moroccan Arabic
    f. Other
        □□□□□□□□□□□□□□□□□□□□
E. Armenian
F. Bengali
G. Cambodian, Mon-Khmer
H. Chinese
    a. Mandarin Chinese
    b. Cantonese (Yue)
    c. Other
        □□□□□□□□□□□□□□□□□□□□
I. Cushite
J. Farsi/Persian
K. French
L. German
M. Greek
N. Gujarati
O. Haitian Creole
P. Hebrew
Q. Hindi
R. Hmong
    a. Hmong Daw (White)
    b. Hmong Njua (Green)

c. Other
□□□□□□□□□□□□□□□□□□□□

S. Italian
T. Japanese
U. Korean
V. Laotian
W. Panjabi
X. Polish
Y. Portuguese
Z. Russian
AA. Tagalog
BB. Thai
CC. Ukrainian
DD. Urdu
EE. Vietnamese
FF. Other
□□□□□□□□□□□□□□□□□□□□

Since some of the response options (others) have fill-in the blanks, CMS OMH suggests that ONC align those options with ISO 639-3 data values. Otherwise we risk having languages that are misspelled and subsequently won't be able to address the macrolanguage concern.

For example:
PAC language question: "What is your preferred language?"
Response options: [all ISO 639-3 languages]

Sex (Assigned at Birth)

Healthy People 2030 recommends collecting additional data about the LGBTQ+ community. The recommendation is that SOGI and disability data be collected in federal programs, health records, and health-related surveys in order to identify opportunities to advance health equity for people with disabilities and members of the LGBTQ+ community.

CMS Office of Minority Health (OMH) recognizes that Section 4302 of the Affordable Care Act requires HHS to develop uniform data collection standards. CMS OMH also acknowledges that aligning the sex at birth question with additional sexual orientation and gender identity (SOGI) questions will increase accuracy and patient-centeredness.

Specifically, CMS OMH supports/recommends the (1) updating the sex assigned at birth question to The Fenway Institute's recommendation of including sex assigned at birth and gender identity as a two-part question. (Please see below) and (2) making asking the questions in this format a requirement, rather than optional.

The Fenway Institute's SOGI Recommendation

Sexual orientation[1]

(1) Do you think of yourself as (Check one):

- ❑ Straight or heterosexual
- ❑ Lesbian, gay, or homosexual
- ❑ Bisexual
- ❑ Additional category (e.g. queer, pansexual, asexual). Please specify _____.
- ❑ Don't know
- ❑ Choose not to disclose

Gender identity[2]

(2) What is your current gender identity? (Check all that apply):

- ❑ Female
- ❑ Male
- ❑ Transgender Woman/Transgender Female
- ❑ Transgender Man/Transgender Male
- ❑ Additional category (e.g. non-binary, genderqueer, gender-diverse, or gender fluid). Please specify _____.
- ❑ Choose not to disclose

(3) What sex were you assigned at birth? (Check one):

- ❑ Male
- ❑ Female

[1] Adapted from Grasso C, Dunn M, "Collecting sexual orientation and gender identity (SOGI) data" course, fall 2020. Boston: National LGBTQIA+ Health Education Center, The Fenway Institute. https://www.lgbtqiahealtheducation.org/courses/collecting-sexual-orientation-and-gender-identity-sogi-data-fall-2020/

[2] Ibid.

Sexual Orientation and Gender Identity (SOGI)

Healthy People 2030 recommends collecting additional data about the LGBTQ+ community. The According to an estimate released by Gallup, in February of 2021, 5.6% of Americans identify as lesbian, gay, bisexual, or transgender (LGBT) individuals. A 2019 article published in the SAGE Journal states that members of the LGBTQ+ community consistently experience unequal treatment when receiving services from health care providers. This includes health care experiences that are stressful, stigmatizing, homophobic, and transphobic. LGBTQ+ people are less likely to experience satisfaction in health care settings, less likely to seek medical services than non LGBTQ+ individuals, receive less benefit from medical services, and experience communication challenges with healthcare professionals. Patients are more likely to be satisfied and engaged in their care when they are served by a provider who is culturally congruent with the lived experience of underserved populations.

Healthy People 2030 recommends collecting additional data about the LGBTQ+ community. The recommendation is that SOGI and disability data be collected in federal programs, health records, and health-related surveys in order to identify opportunities to advance health equity for people with disabilities and members of the LGBTQ+ community

Executive Order 13985, issued on January of 2021, called upon agencies to identify and work to redress inequities in their policies and programs that create barriers to equal opportunity to ensure that everyone, including LGBTQ+ people, can reach their highest potential.

Additionally, including SOGI questions is a first step in beginning to mitigate and control for many of the challenges associated with known biases imbedded in artificial intelligence, natural language processing, and machine learning. CMS OMH supports sexual orientation and gender inclusion questions provided by The Fenway Institute.

Sexual orientation
Do you think of yourself as (Check one):

- ❑ Straight or heterosexual
- ❑ Lesbian, gay, or homosexual
- ❑ Bisexual
- ❑ Additional category (e.g. queer, pansexual, asexual). Please specify _____.
- ❑ Don't know
- ❑ Choose not to disclose

Gender identity
What is your current gender identity? (Check all that apply):

- ❑ Female
- ❑ Male
- ❑ Transgender Woman/Transgender Female
- ❑ Transgender Man/Transgender Male
- ❑ Additional category (e.g. non-binary, genderqueer, gender-diverse, or gender fluid). Please specify _____.
- ❑ Choose not to disclose

What sex were you assigned at birth? (Check one):

- ❑ Male
- ❑ Female

We also recommend the inclusion of this question[3] about intersex status, developed by interACT in partnership with the Williams Institute at UCLA School of Law:

Were you born with a variation in your physical sex characteristics? (This is sometimes called being intersex or having a Difference in Sex Development (DSD).)

- ❑ No
- ❑ Yes, my chromosomes, genitals, reproductive organs, or hormone functions were observed to be different from the typical male/female binary at birth and/or I have been diagnosed with an intersex variation or Difference of Sex Development
- ❑ I don't know

Section B: Additional Standard

The following section details the CMS OMH recommendation on standards not present in the V2 draft.

Disability Status

According to a WHO publication, over one billion people – about 15% of the global population – live with some form of disability and this number is growing because of population increases, ageing, rise of noncommunicable diseases, and medical advances. The recently endorsed WHA Resolution on the highest attainable standard of health for persons with disabilities requests collaboration between states, international organizations, and other relevant stakeholders, including intergovernmental and nongovernmental organizations, private sector companies, academia, and organizations of persons with disabilities to work together toward strengthening disability inclusion across the wider health sector and in national health agendas.

According to Healthy People 2030, about 1 in 4 people in the United States have a disability. People with disabilities are less likely to get preventative health care services they need to stay healthy. One of the goals for Healthy People 2030 is to Improve health and well-being in people with disabilities, along with several objectives.

The questions in the data standard was developed by a federal interagency committee and reflects the change in how disability is conceptualized consistent with the International Classification of Functioning, Disability, and Health. The question set defines disability from a functional perspective and was developed so that disparities between the 'disabled' and 'nondisabled' population can be monitored. The question set went through several rounds of cognitive and field testing and has been adopted in many federal data collection systems. OMB has encouraged the use of this question set by other federal agencies conducting similar population studies due to the extensive testing used in the development of these measures, including the findings that alternative measures did not test as well. Cognitive testing of these questions revealed that the six questions must be used as a set to assure a meaningful measure of disability.

The CMS Office of Minority Health (OMH) recommends that the proposed US Core Data for Interoperability (USCDI) standards V2 Draft align with the 2011 standards related to Disability Status, as outlined below.

HHS 2011 Data Standard:

1. Are you deaf or do you have serious difficulty hearing?
   a. ____ Yes
   b. ____ No
2. Are you blind or do you have serious difficulty seeing, even when wearing glasses?
   a. ____ Yes
   b. ____ No
3. Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions? (5 years old or older)
   a. ____ Yes
   b. ____ No
4. Do you have serious difficulty walking or climbing stairs? (5 years old or older)
   a. ____ Yes
   b. ____ No
5. Do you have difficulty dressing or bathing? (5 years old or older)
   a. ____ Yes
   b. ____ No
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? (15 years old or older)
   a. ____ Yes
   b. ____ No

Justification

- Section 4302 of the Affordable Care Act, required HHS to develop uniform data collection standards. The disability data elements were developed in response.
- The standards have been field and cognitive tested and adopted in other federal data collection.
- This information is critical for stratifying data and identifying disparities in population health, healthcare access and health outcomes.
- This standard will help to align with existing Federal data collection instruments and increases CMS' ability to analyze health disparities in Medicare, which is critically necessary for quality improvement and responsiveness to public health emergencies such as COVID-19.
- Healthy People 2030 contains a goal and objectives to Improve the health and well-being in people with disabilities.