

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

Date: April 29, 2022

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 V3 Draft, as outlined below.

1. Feedback on Sex, Gender Identity and Sexual Orientation Elements

- CMS proposes that, given the robust evidence present in the recent National Academies of Sciences, Engineering, and Medicine's (NASEM) report, titled Measuring Sex, Gender Identity, and Sexual Orientation, which has recommendations on how to collect sex, sexual orientation, and gender identity data in a standardized, relevant, and reliable manner (<https://dpcpsi.nih.gov/sgmro/reports>), ONC considers adopting the recommendations in the NASEM report.
- While USCDI Draft V3 Sex Assigned at Birth designation aligns with NASEM's recommendation for capturing data on sex assigned at birth with the exception of 'Prefer not to answer', the Gender Identity and Sexual Orientation designations do not. According to NASEM's report, some options provided for these elements within ONC's current definitions may employ Eurocentric terminology, leaving out terms like "Two-Spirit" or "same gender loving" employed by tribal communities or communities of color at a higher rate. Currently the standard does not capture intersex or differences in sex development (DSD) status information as part of sexual identity in line with NASEM's recommendation, which may be advisable given health disparities experienced by intersex populations. NASEM also states that options like Female-to-Male Transgender identity can present inclusiveness issues, as specific transgender identity terms may be less well-known outside the LGBTQI+ community. This can result in inaccurate or incomplete data.
- The standard references the HL7® Gender Harmony Project's proposals to add Sex for Clinical Use, Pronouns, and Recorded Sex or Gender to replace Sex Assigned at Birth, while NASEM evidence supports the use of Sex Assigned at Birth as the most suitable measure.

2. Addition to standard, not present in the V3 Draft

- Use of an interpreter
 - CMS OMH proposes consideration of a new element as follows: "Do you need or want an interpreter to communicate with a doctor or health care staff?" in line with Logical Observation Identifiers Names and Codes (LOINC®) 54588-9. This data element can add important context about the supports a particular patient requires in order to address literacy or language barriers.