

April 15, 2024

Micky Tripathi, Ph.D., M.P.P., National Coordinator for Health IT
Steven Posnack, M.S., M.H.S., Deputy National Coordinator for Health IT
Office of the National Coordinator for Health Information Technology
Office of the Secretary, United States Department of Health and Human Services

Re: Request for Public Comment, Draft United States Core Data for Interoperability (USCDI) v5

Submitted electronically to

<https://www.healthit.gov/isa/united-states-core-data-interoperability-uscdi#draft-uscdi-v5>

Dear Dr. Tripathi and Mr. Posnack,

On behalf of the 10 undersigned healthcare organizations, we write in response to the request for public comment from the Office of the National Coordinator for Health Information Technology (ONC) on the Draft United States Core Data for Interoperability Version 5 (Draft USCDI v5).

Draft USCDI v5 includes existing and new data classes and elements that will support the goals of ONC and the U.S. Department of Health and Human Services (HHS) to improve patient care and advance equity, diversity, and accessible healthcare.¹ We strongly support Draft USCDI v5 proposal to add *Name to Use*, *Pronoun*, and *Sex Parameter for Clinical Use* to the base set of data that certified health IT modules must be capable of exchanging. Below we provide feedback on existing and new data elements included in Draft USCDI v5 and offer recommendations for ways to improve these elements.

I. Feedback on USCDI v5 Sexual Orientation and Gender Identity Data Elements

First implemented in 2020, the USCDI is a curated set of health data classes and elements that establishes a baseline for which data must be exchangeable between entities for a wide range of uses.² In 2021, Version 2 of USCDI added three data classes and twenty-two data elements in support of advancing health equity, including sexual orientation and gender identity (SOGI) and social determinants of health. With this step, USCDI v2 required that SOGI data collected in

¹ See, for example, U.S. Department of Health and Human Services, “Agency Equity Action Plan”, available at <https://www.hhs.gov/sites/default/files/hhs-equity-action-plan.pdf> (last accessed March 2024); U.S. Department of Health and Human Services, “Sexual Orientation and Gender Identity Action Plan” available at <https://www.hhs.gov/sites/default/files/hhs-sogi-data-action-plan.pdf> (last accessed March 2024)

² Office of the National Coordinator for Health Information Technology, “Cures Act Final Rule: United States Core Data for Interoperability,” <https://www.healthit.gov/sites/default/files/page2/2020-03/USCDI.pdf>

electronic health records (EHR) be made interoperable, provided clear direction for the standardized electronic exchange of EHR data, and laid a foundation for systematized capture and use of these data.³

We strongly support the continued inclusion of SOGI data elements in Draft USCDI v5, which is critical to support the provision of patient-centered, high-quality care. Evidence demonstrates that SOGI correlates with health disparities related to disease burden, risk behaviors, access to health care and insurance coverage.⁴ In combination with anatomical inventory, race and ethnicity data, and other variables, these data have helped identify inequities related to mental and behavioral health conditions, exposure to violence, COVID-19 incidence, HIV prevention and treatment needs, cancer screening rates, and tobacco use.⁵ Understanding a patient's identity not only helps inform therapeutic or preventive services, but may also provide information relevant to a patient's family structure and convey a cultural responsiveness to LGBTQI+ patients. Collecting these data is critical to leverage data and build evidence to advance health equity for LGBTQI+ communities, aligning with HHS goals articulated in its Agency Equity Action Plan required under Executive Order 13985 and its Sexual Orientation and Gender Identity (SOGI) Data Action Plan required under Executive Order 14075.⁶ Collecting SOGI data through USCDI v5 is pivotal to better understand, address, and eliminate disparities, and to support the provision of responsive, high-quality, patient-centered care.

While we support SOGI data elements in Draft USCDI, we offer recommendations to support the improvement of the existing measures. Notably, ONC requires that certified EHR systems use specific standards to capture SOGI data (e.g., SNOMED CT). However, some of the existing SNOMED CT codes for SOGI are out of date and not affirming of LGBTQI+ people. For example, many transgender people consider several terms to be offensive.⁷ We recommend that ONC create guidance for vendors and healthcare organizations to encourage them to not use or display terms such as "homosexual," "transsexual," or "hermaphrodite" and instead to display terms such as "gay or lesbian," "transgender," or "intersex." To ensure that the required standard is inclusive of up-to-date terminology and does not retain outdated and potentially offensive terms, standard developers can look to examples such as the Gender Harmony Project's

³ Kellan E. Baker, Eleanor Sarkodie, Jennafer Kwait, Caroline Medina, Asa Radix, and Risa Flynn, 2023: *Advancing Sexual and Gender Minority Population Health Using Electronic Health Record Data* American Journal of Public Health **113**, 1287_1289, <https://doi.org/10.2105/AJPH.2023.307467>

⁴ National Academies of Sciences, Engineering, and Medicine, "Measuring Sex, Gender Identity, and Sexual Orientation" (Washington: The National Academies Press, 2022), available at <https://www.nap.edu/catalog/26424/measuring-sex-gender-identity-and-sexual-orientation>

⁵ Kellan E. Baker, Eleanor Sarkodie, Jennafer Kwait, Caroline Medina, Asa Radix, and Risa Flynn, 2023: *Advancing Sexual and Gender Minority Population Health Using Electronic Health Record Data* American Journal of Public Health **113**, 1287_1289, <https://doi.org/10.2105/AJPH.2023.307467>

⁶ Exec. Order. 14075, Advancing Equality for Lesbian, Gay, Bisexual, Transgender, Queer, and Intersex Individuals, 87 Fed. Reg. 37,189 (June 15, 2022).

⁷ Ram A, Kronk CA, Eleazer JR, Goulet JL, Brandt CA, Wang KH. Transphobia, encoded: an examination of trans-specific terminology in SNOMED CT and ICD-10-CM. *J Am Med Inform Assoc.* 2022 Jan 12;29(2):404-410. doi: 10.1093/jamia/ocab200. PMID: 34569604; PMCID: PMC8757305.

collaborative efforts to update Health Level 7 (HL7) terminology to align with both clinically useful and culturally appropriate concepts of sex and gender.¹⁵ We also urge ONC to leverage its power as the health IT agency of the U.S. government and work with SNOMED to modernize its language regarding LGBTQI+ patients expeditiously.

II. Feedback on Draft USCDI v5 New Data Elements: Sex Parameter for Clinical Use, Name to Use, Pronouns

We support the inclusion of new data elements for Pronouns, Name to Use, and Sex Parameter for Clinical Use in Draft USCDI v5. Collecting data elements on Name to Use and Pronouns is essential to provide affirming care to all patients, especially transgender and nonbinary patients, as well as other patients who may not use their legal or given name for various reasons. For example, according to a 2022 nationally representative survey conducted by Center for American Progress, 21 percent of transgender respondents reported that their doctor or other health care provider intentionally misgendered them or used the wrong name.⁸ We believe that—paired with comprehensive training—adding new data elements on Name to Use and Pronouns will support efforts to provide patient-centered, affirming care. We appreciate the inclusion of examples and usage notes clarifying that this information about Pronouns and Names to Use should be self-reported by the patient. Accurate information about Sex Parameter for Clinical Use is also helpful when clinicians or other health system professionals are interacting with specimens for testing that must be submitted for laboratory assessment. Incorporating these new data elements into USCDI will help to improve the care and experiences of gender diverse patients, which is especially critical in light of the recent onslaught of efforts to ban access to medically necessary care for transgender populations.

III. Recommendations for Additional Data Elements

In future versions of USCDI, ONC should add data element(s) related to sex characteristics that allow for the measurement of intersex status. Doing so will support efforts to provide affirming care to people with intersex traits and aligns with the goals of the HHS Data Action Plan to “test and incorporate measures of sex characteristics (including self-identification of the intersex population)”.⁹ The addition of a data element to support self-identification of intersex status is critical to improve the delivery of affirming care to people with intersex traits who continue to experience heightened mental and physical health disparities driven by stigmatization, prejudice,

⁸ Caroline Medina & Lindsay Mahowald, *Discrimination and Barriers to Well-being: the State of the LGBTQI+ Community in 2022*, CTR. FOR AM. PROGRESS (January 12, 2023), <https://www.americanprogress.org/article/discrimination-and-barriers-to-well-being-the-state-of-the-lgbtqi-community-in-2022/>

⁹ U.S. Department of Health and Human Services, "HHS SOGI Data Collection and Action Plan," available at <https://www.hhs.gov/sites/default/files/hhs-sogi-data-action-plan.pdf>

and discrimination.¹⁰ We strongly encourage ONC to work intersex communities, interACT: Advocates for Intersex Youth, LGBTQI+ stakeholders, intersex data experts, and health IT standard-setting entities such as SNOMED to develop interoperable health IT standards that reflect the categories used by intersex people to describe themselves. We encourage ONC to work with intersex leaders and researchers to help develop culturally competent health IT standards to better serve members of the intersex community.

We also encourage ONC to make clear that health care providers serving Indigenous patients, whether in urban metropolitan areas or near American Indian/Alaska Native reservations, should consider making Two-Spirit a response option for Indigenous patients in response to both sexual orientation and gender identity questions. Doing so aligns with the recommendations of the 2022 National Academy of Sciences, Medicine and Engineering report,¹¹ HHS Data Action Plan goal to support self-identification of Two-Spirit populations in collections of demographic data,¹² and the Indian Health Service (IHS) standard for data capture of sexual orientation and gender identity information released in 2023.¹³ For the sexual orientation question this Two-Spirit response option could correspond to SNOMED CT code nullFlavor OTH. For gender identity it could correspond to code nullFlavor OTH. We urge ONC to support the adoption of the IHS standard and work with SNOMED to add Two-Spirit as a response option for individuals who self-report that they identify as American Indian or Alaska Native.

IV. Recommendations for Implementation

Importantly, use of existing SOGI data elements and adoption of new data elements in USCDI v5 must be paired with comprehensive cultural competency training and education for those collecting the data, including clinicians and frontlines staff. Doing so is essential to support efforts to provide culturally responsive, affirming care. To promote transparency and informed decision-making, healthcare organizations should also clearly and accessibly post information about the purpose of the data collection, how data will be used, with whom and how data may be shared, the voluntary nature of self-reporting, and relevant nondiscrimination and privacy

¹⁰ Caroline Medina & Lindsay Mahowald, *Key Issues Facing People with Intersex Traits*, CTR. FOR AM. PROGRESS (October 26, 2021), <https://www.americanprogress.org/article/key-issues-facing-people-intersex-traits/#:~:text=Intersex%20people%20face%20high%20rates%20of%20discrimination%20and%20stigma&text=The%20high%20rates%20of%20economic,as%20shown%20in%20Figure%204.>

¹¹ National Academies of Sciences, Engineering, and Medicine. 2022. *Measuring Sex, Gender Identity, and Sexual Orientation*. Washington, DC: The National Academies Press. <https://doi.org/10.17226/26424>.

¹² U.S. Department of Health and Human Services, "HHS SOGI Data Collection and Action Plan," available at <https://www.hhs.gov/sites/default/files/hhs-sogi-data-action-plan.pdf>

¹³ Indian Health Service, "IHS Includes Sexual Orientation and Gender Identity in Electronic Health Records" (June 29, 2023), available at <https://www.ihs.gov/newsroom/ihs-blog/june-2023-blogs/ihs-includes-sexual-orientation-and-gender-identity-in-electronic-health-records/>

protections. Patients should be clearly informed that they have the right to ask their provider or their health practice not to exchange their SOGI information.

V. Conclusion

We appreciate ONC's dedication to improving quality of care, enabling public health data interoperability, and enhancing LGBTQI+ health equity. We believe that use of existing SOGI data elements and adoption of new data elements in USCDI v5 is important to improve delivery of patient-centered care, support clinical decision-making, and promote population health.

Thank you for the opportunity to comment on USCDI v5. Should you have any questions, please contact Caroline Medina, Director of Policy for Whitman-Walker Institute at cmedina@whitman-walker.org.

Sincerely,

Apicha Community Health Center
Beth Israel Deaconess Medical Center/BILH
Callen-Lorde Community Health Center
Cascade AIDS Project & Prism Health
Chase Brexton Health Care
Circle Care Center
Legacy Community Health
The Fenway Institute
Trillium Health
Whitman-Walker Institute