

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

Dear Dr. Tripathi and Mr. Posnack,

On behalf of the 10 undersigned organizations focused on LGBTQI+ equity, 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).

We strongly support the 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. These additions 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 including for LGBTQI+ people. LGBTQ people continue to experience health disparities related to disease burden, risk behaviors, access to health care and insurance coverage.² More inclusive data inclusion in USCDI can help reduce these disparities for LGBTQI+ communities.

We support the continued inclusion of sexual orientation and gender identity (SOGI) data elements in Draft USCDI v5, which are pivotal to better understand, address, and eliminate disparities, and to support the provision of responsive, high-quality, patient-centered care. We recommend that ONC create guidance for vendors and healthcare organizations to use inclusive, up-to-date terminology rather than terms that can be seen as offensive or out-of-date.

Similarly, 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.

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 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>

As future versions of USCDI are developed, we request the addition of data elements related to sex characteristics allowing for the measurement of intersex status. The development of these measures should be conducted in partnership with intersex communities, interACT: Advocates for Intersex Youth, LGBTQI+ stakeholders, intersex data experts, and health IT standard-setting entities such as SNOMED. 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.

Thank you for the opportunity to comment on USCDI v5. We support these updates and know they will be helpful in advancing LGBTQI+ health equity. Please reach out with any questions to Naomi Goldberg, Executive Director, Movement Advancement Project, naomi@mapresearch.org.

Sincerely,

CenterLink: The Community of LGBTQ Centers
FORGE, Inc.
GLMA: Health Professionals Advancing LGBTQ+ Equality
Howard Brown Health
interACT: Advocates for Intersex Youth
Movement Advancement Project
National Health Law Program
National LGBTQI+ Cancer Network
National LGBTQ Task Force
The Trevor Project