United States Senate
WASHINGTON, DC 20510

June 27, 2024

Office of the National Coordinator for Health Information Technology
Office of the Secretary, United States Department of Health and Human Services
U.S. Department of Health and Human Services
330 C Street SW
Washington, D.C. 20201

Dear Dr. Tripathi,

We write to offer our full support for the Office of the National Coordinator for Health Information Technology's (ONC) proposed modifications to the United States Core Data for Interoperability Version 5 (USCDI v5), which sets standards for sharing patient information between health care systems. We offer recommendations for further refining standards to improve how sexual orientation and gender identity information is collected and shared across different health care systems, making health care more inclusive, accurate, and patient-centered.

The U.S. Department of Health and Human Services (HHS) mandates use of the USCDI standards in electronic health record systems to promote consistent and secure information exchange, patient care coordination, interoperability, and positive outcomes across the United States health care system. Your office recently proposed an update to these standards including the addition of preferred name and pronouns and sex paramater for clinical use. These changes are critical for improving care for members of the LGBTQ+ community. In addition to these changes, we also recommend changing some of the existing standards to ensure alignment with HHS policy on sexual orientation and gender identity (SOGI) data collection, including data about indigenous patients, and to ensure health care providers and staff are culturally competent and transparent about how sensitive patient data will be used and protected.

Electronic health record systems that only offer "male" or "female" options for recording the sex of a patient and that do not provide a place to enter preferred names and pronouns may result in a patient's medical records misgendering them and failing to accurately represent their identity and medical history. This devalues the patient and can lead to a health care provider diagnosing or treating a patient without relevant information. This oversight may result in inadvertent discrimination that compromises a patient's trust in the health care system, puts their health at risk, and diminishes efforts to promote inclusive and equitable health care access for all people, regardless of their gender identity.

The proposed addition of preferred names and pronouns to the USCDI will enhance care for members of the LGBTQ+ community, ensuring that health care providers respect and acknowledge patients' identities. For example, if a transgender patient prefers to be addressed with she/her pronouns, documenting this in their health record helps avoid misgendering and fosters a more respectful and comfortable environment for the patient. The proposed addition of sex parameters for clinical use will allow providers to consider a patient's sex based on relevant medical needs, such as surgical history or hormone levels, rather than simply their sex at birth. This approach fosters more accurate and personalized medical care. For example, documenting the sex parameter for clinical use may ensure that a transgender man undergoing hormone therapy receives accurate heart health assessments and appropriate medication adjustments based on his current health status rather than his sex assigned at birth.

The inclusion of SOGI data in the USCDI is essential for addressing health disparities faced by LGBTQ+ individuals. It ensures that health records are inclusive and aids in public health research and policy-making. However, some existing terms used to capture SOGI data are outdated and offensive to some in the LGBTQ+ community. We urge the ONC to update these terms to be more respectful and culturally sensitive.

To further promote health equity, we also recommend adding a way to record intersex status and Two-Spirit as an option for Indigenous patients. The latter is consistent with standards set by the Indian Health Services for capturing SOGI data. We suggest providing cultural competency training for health care providers on using SOGI data and ensuring transparency about how patient data will be used.

Patients should be informed of their rights regarding the exchange of their SOGI information, which is important for fostering trust in the health care system. Finally, because the addition of sensitive information like SOGI data to electronic health records may heighten privacy risks, the ONC must ensure the protection of patient data through all means possible.

In summary, we fully support the proposed updates to USCDI v5, as they represent significant strides in promoting inclusivity and health equity. We urge you to consider our recommendations for further improvements and to implement these updates promptly to enhance the quality of care for all patients.

We appreciate the ONC’s commitment to improving health care quality and safety by facilitating seamless data exchange among different health care systems. We look forward to the successful implementation of these critical updates.

Sincerely,

Sincerely,

Ron Wyden
Ron Wyden
United States Senator

Jeffrey A. Merkley
Jeffrey A. Merkley
United States Senator

CC:

Steven Posnack, M.S., M.H.S., Deputy National Coordinator for Health Information Technology