

April 15, 2021

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) v2

Submitted electronically to <https://www.healthit.gov/isa/united-states-core-data-interoperability-uscdi>

Dear Dr. Tripathi and Mr. Posnack,

The Fenway Institute at Fenway Health and a coalition of 65 partner organizations working in health care, LGBTQIA+ equality, sexual and gender minority (SGM) health, and HIV prevention and care submit the following comment regarding ONC's Request for Public Comment on the Draft USCDI v2 posted in January, 2021. The Fenway Institute is the research, education and training, and policy arm of Fenway Health, a federally qualified health center and Ryan White Part c HIV clinic in Boston, Massachusetts. We provide care to about 35,000 patients every year. Half of our patients are LGBTQIA+. About 2,300 of our patients are people living with HIV.

We were pleased to learn from Dr. Tripathi's keynote address at ONC's annual meeting March 29th that one of ONC's "top goals" is "centering health equity."¹ We share ONC's vision about the promise of leveraging health IT to build a nationwide, interoperable, value-based, person-centered health system. The Fenway Institute has engaged with ONC since 2012 on issues related to the adoption and implementation of national sexual orientation and gender identity (SOGI) health IT standards. We appreciate your responsiveness to our priorities. In 2015, ONC adopted SOGI standards as required fields in the "demographics" section of the 2015 Edition Base Electronic Health Record (EHR) Definition certification criteria, making SOGI part of all Certified Electronic Health Record Technology (CEHRT) products. Further, in addition to being required fields for EHR certification, SOGI has also been included in the Interoperability Standards

¹ Jercich K, "ONC's top goals: Interoperability, alignment, equity." Health IT News. March 29, 2021. <https://www.healthcareitnews.com/news/oncs-top-goals-interoperability-alignment-and-equity>

Advisory since it was first published in 2015. SOGI standards have achieved steadily increasing and high levels of maturity and adoption since 2015,² as reflected in the 2021 reference edition of ONC's Interoperability Standards Advisory (pages 43-45).³ We welcome the opportunity to review and comment on the current USCDI v1 and on the proposed USCDI v2.

Our comment is structured as requested in response to the three requests in ONC's call for public comment.

1. Review the current USCDI v1 and comment on whether any applicable standards should be updated in final USCDI v2.

We are grateful that ONC adopted SOGI elements in October 2015 based on research that the Fenway Institute and the Center for American Progress conducted with a diverse group of community health center patients, and which were recommended by a broad range of stakeholders, including the Mayo Clinic, the Trust for America's Health, and Massachusetts General Hospital. We agreed with ONC in October 2015, when it required "that Health IT modules enable a user to record, change, and access SO/GI [sexual orientation and gender identity] to be certified to the 2015 Edition 'demographics' certification criterion." In this final rule, ONC and CMS explained that:

The 2015 Edition proposed rule also included a criterion to record a patient's sexual orientation and gender identity (SO/GI) in a structured way with standardized data. Where the patient chooses to disclose this information, the inclusion of this information can help those within the patient's care team to have more information on the patient that can aid in identifying interventions and treatments most helpful to the particular patient. Additionally, sexual orientation and gender identity can be relevant to individual treatment decisions; for example, transgender men who were assigned female at birth should be offered a cervical exam, as appropriate.

Finally, we strongly agreed with this statement:

² Grasso C, Goldhammer H, Funk D, King D, Reisner SL, Mayer KH, and Keuroghlian AS (2019). Required Sexual Orientation and Gender Identity Reporting by US Health Centers: First-Year Data *American Journal of Public Health* 109, 1111_1118, <https://doi.org/10.2105/AJPH.2019.305130>

³ Office of the National Coordinator of Health Information Technology (2021). *2021 Interoperability Standards Advisory*. Reference Edition. <https://www.healthit.gov/isa/sites/isa/files/inline-files/2021-ISA-Reference-Edition.pdf>

CMS and ONC believe including SO/GI in the “demographics” criterion represents a crucial step forward to improving care for LGBT communities.⁴

We therefore request that the Patient Demographics requirements of USCDI v1 be expanded to include sexual orientation, gender identity, intersex status, name used, and pronouns in USCDI v2.

USCDI v1 Patient Demographics include:

Patient Demographics

- First Name
- Last Name
- Previous Name
- Middle Name (incl Middle Initial)
- Suffix
- Birth Sex
- Date of Birth
- Race
- Ethnicity
- Preferred Language
- Current Address
- Previous Address
- Phone Number
- Phone Number Type
- Email Address

In addition to collecting and tracking demographic data such as the patient’s sex, age, race, ethnicity, geography, and preferred language, knowing a patient’s sexual orientation, gender identity, intersex status, named used, and pronouns is important for health care providers and public health researchers.

Knowing a patient’s current gender identity and sex assigned at birth, as well as their anatomical inventory, is important for informing clinical decision support as well as understanding healthcare organization and population-level health

⁴ Department of Health and Human Services, Centers for Medicare and Medicaid Services: 42 CFR Parts 412 and 495 [CMS-3310-FC and CMS-3311-FC], RINs 0938-AS26 and 0938-AS58. Medicare and Medicaid Programs; Electronic Health Record Incentive Program—Stage 3 and Modifications to Meaningful Use in 2015 through 2017. Released October 6, 2015. Page 408. <https://s3.amazonaws.com/public-inspection.federalregister.gov/2015-25595.pdf> Accessed March 24, 2021.

disparities.⁵ There are striking disparities in accessing preventive services that correlate with sexual orientation and gender identity, as well as race/ethnicity and other factors. For example, lesbian and bisexual women are less likely to access cervical cancer screening and mammograms. This is also true of Black and Latina women. Lesbian and bisexual women may also be at elevated risk of breast and ovarian cancer related to nulliparity. The availability of data about sex, gender, and sexual orientation in an EHR is useful for healthcare systems in identifying and addressing disparities among sexual and gender minority patients, which are an NIH-recognized health disparity group.

2. Review and comment on the ONC proposed Draft USCDI v2 data elements and any applicable standards.

The Draft USCDI v2 Patient Demographics are identical to those in USCDI v1. Please expand them to include sexual orientation, gender identity, intersex status, name used, and pronouns.

In our June 2019 comment on the 21st Century Cures Act: Interoperability, Information Blocking, and the ONC Health IT Certification Program (RIN 0955-AA01), we urged ONC to include existing, national SOGI standards from the “demographics” section of the 2015 Base EHR Definition in the “Patient Demographics” section of the United States Core Data for Interoperability (USCDI). We stated that this would provide both regulatory and technical continuity between then existing health IT certification requirements and USCDI, thus advancing the overall goal of nationwide interoperability. SOGI standards have achieved much higher levels of maturity and adoption since their inclusion in the demographics section of the 2015 Base EHR Definition, and are thus ideal candidates for USCDI.

Given the existence of mature, widely adopted, national SOGI standards and previous regulatory health IT guidance including SOGI data as demographic fields, USCDI should include SOGI in its “Patient Demographics” section. It should also include intersex status, name used, and pronouns. In addition to being of clinical value for patients, providers, and other users of health IT, the availability of structured SOGI demographic data will ease processes of patient-matching and

⁵ Grasso C, Goldhammer H, Brown RJ, Furness BW (2020). Using sexual orientation and gender identity data in electronic health records to assess for disparities in preventive health screening services. *International Journal of Medical Informatics*_Volume 142, October 2020, 104245. <https://doi.org/10.1016/j.ijmedinf.2020.104245>

identity-proofing during transfers of care or instances of health information exchange.

In addition to the reasons described above for including SOGI in USCDI, increasing SOGI data collection has been a priority of the health care sector and the LGBT community^{6,7} for many years. This is why the Institute of Medicine (IOM)⁸, the Joint Commission,⁹ and CMS¹⁰ recommend asking questions about SOGI in clinical settings and including these data in EHR systems to improve quality of care. It is also why the Bureau of Primary Health Care at HRSA requires community health centers to report the SOGI of their more than 20 million adult patients.¹¹ It is why the National Academies of Science, Engineering and Medicine¹² and the PhenX Toolkit¹³ recommend collecting SOGI data.

The inclusion of these elements will ensure that USCDI is in alignment with other standards development organizations such as HL7 and SNOMED. HL7's Gender Harmony Project, which has gone through the balloting process, has proposed the inclusion of the following data elements: gender identity, recorded sex or gender, sex for clinical use, name to use, and pronouns. SNOMED has established a sex and gender clinical group to review and update data elements with regard to sex, sexual orientation, gender identity and related anatomy. Fenway Health researchers are active participants in both the SNOMED and HL7 working groups.

⁶ Cahill, S., & Makadon, H. (2013). Sexual orientation and gender identity data collection in clinical settings and in Electronic Health Records: A key to ending LGBT health disparities. *LGBT Health*. 1(1). 1-8.

⁷ The Fenway Institute, the Center for American Progress, and 103 other health care organizations (2015, May 29). Public Comment on 2015 Edition Health Information Technology (Health IT) Certification Criteria, 2015 Edition Base Electronic Health Record (EHR) Definition, and ONC Health IT Certification Program Modifications published March 30, 2015. <https://fenwayhealth.org/wp-content/uploads/ONC-Health-IT-Certification-Criteria-rule-Fenway-CAP-public-comment-FINAL-052915.pdf>

⁸ Institute of Medicine. Committee on Lesbian, Gay, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities; Board on the Health of Select Populations; Institute of Medicine. *The Health of Lesbian, Gay, Bisexual, and Transgender (LGBT) People: Building a Foundation for Better Understanding*, Washington, DC: National Academies Press, 2011. http://www.nap.edu/catalog.php?record_id=13128. Accessed November 24, 2015.

⁹ The Joint Commission. *Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care: A Roadmap for Hospitals*. Oakbrook Terrace, IL: The Joint Commission, 2010, page 11.

¹⁰ Centers for Medicare and Medicaid Services (2015). *Equity Plan for Medicare Beneficiaries*. https://www.cms.gov/About-CMS/Agency-Information/OMH/OMH_Dwnld-CMS_EquityPlanforMedicare_090615.pdf

¹¹ Cahill S (2018). Legal and policy issues for LGBT patients with cancer or at elevated risk of cancer. *Seminars in Oncology Nursing*. 34(1):90-98.

¹² National Academies of Sciences, Engineering, and Medicine 2020. *Understanding the Well-Being of LGBTQI+ Populations*. Washington, DC: The National Academies Press. <https://doi.org/10.17226/25877>

¹³ RTI International (2021, February 23). *PhenX Toolkit*. Version 37.0. <https://www.phenxtoolkit.org/domains/view/10000>

It is especially important that SOGI data collection and use be standardized and, at a minimum, encouraged, and even better, incentivized or required, so that we can increase our understanding of SGM health disparities with high quality clinical data. It is also important to cross tabulate SOGI data with other demographic data to understand the intersection of SGM disparities with those affecting members of racial and ethnic minority groups, people with disabilities, immigrants and non-English speakers, people living in rural areas, and any other disparity populations. Also, given the rapidly changing terminology in the field of sexual and gender minority health, we encourage ONC to allow for future updates to response options regarding sexual orientation and gender identity.

3. Review the Level 2 data elements that were not included in the Draft USCDI v2 and comment on their potential inclusion in the final USCDI v2 with any applicable standards.

For the reasons stated above, we believe that the Level 2 data elements of gender identity and sexual orientation should be included in the final USCDI v2, along with intersex status, name used, and pronouns.

Based on many years of experience collecting and using patient SOGI data in Electronic Health Records (EHRs), advocating for inclusion of SOGI in national health IT systems and surveys, and training health centers and other organizations in how to collect and use SOGI to improve quality of care, the Fenway Institute and our colleague organizations strongly encourage ONC to include SOGI standards in USCDI v2, including sexual orientation, gender identity, intersex status, named used, and pronouns.

The Fenway Institute and other health policy advocates, researchers, and providers would welcome opportunities to engage ONC staff, the ONC USCDI Task Force, and the ONC Health IT Policy Committee during this process. We are working to improve upon existing SOGI standards through the ability to accommodate new and up-to-date SNOMED codes with better technical functionality for interoperability and better cultural competency for LGBTQIA+ patients. We will also continue to engage HL7 to ensure ongoing review and adoption of updated codes into FHIR standards. In addition, the Fenway Institute and other health stakeholders listed below are engaging a number of other federal partners, including the Consensus Study Panel on Measuring Sex, Gender Identity, and Sexual Orientation for the National Institutes of Health, and the National Library of Medicine, to promote more mature and effective terminology for SOGI.

Thank you for the opportunity to comment on USCDI v2. Should you have any questions, please contact Sean Cahill, PhD, Director of Health Policy Research at the Fenway Institute, at scahill@fenwayhealth.org or 617-927-6016.

Sincerely,

The Fenway Institute
Advocates for Youth
AIDS Foundation Chicago
Association of Nurses in AIDS Care
BAGLY, Inc. (Boston Alliance of LGBTQ Youth)
Bayard Rustin Liberation Initiative
BiNet USA
The Boston Foundation
Boston Indicators at the Boston Foundation
Callen-Lorde Community Health Center
Cascade AIDS Project
The Center for American Progress
The Center for HIV Law and Policy
Center for LGBTQ Economic Advancement & Research (CLEAR)
Center for Public Health and Human Rights, Johns Hopkins Bloomberg School of
Public Health
Center Link: The Community of LGBT Centers
Chase Brexton Health Services
Community Research Initiative of New England, Inc.
CrescentCare
Equality Ohio
Equitas Health
FORGE, Inc.
GLBTQ Legal Advocates and Defenders
GMHC
God's Love We Deliver, Inc.
Human Rights Campaign
HIV/STI Intervention & Prevention Studies, University of Minnesota
interact: Advocates for Intersex Youth
International Association of Providers of AIDS Care
John Snow, Inc.
Latino Commission on AIDS
Legacy Community Health
Let's Kick ASS AIDS Survivor Syndrome

LGBT Elders of Color
LGBT Technology Institute
Los Angeles LGBT Center
Lyon-Martin Health Services
Massachusetts Transgender Political Coalition
Mayo Clinic
Movement Advancement Project
MPact: Global Action for Gay Men's Health and Rights
National Association of Community Health Centers
NASTAD
National Black Justice Coalition
National Center for Transgender Equality
National Coalition for LGBT Health
National Equality Action Team (NEAT)
National LGBT Cancer Network
National LGBTQ Task Force
National Working Position Coalition
New England Association of HIV Over 50
North Carolina AIDS Action Network
Prism Health
SAGE (Services and Advocacy for GLBT Elders)
SAGE New Orleans
School of Public Health, Rutgers University
The 6:52 Project Foundation, Inc.
TPAN
Transgender Law Center
Transgender Legal Defense & Education Fund
Transhealth Northampton
Treatment Action Group
The Trevor Project
Unity Fellowship of Christ Church—NYC
VOCAL—NY
Whitman Walker Institute