April 17, 2023

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) v4

Submitted electronically to https://www.healthit.gov/isa/united-states-core-data-interoperability-uscdi#comment-form

Dear Dr. Tripathi and Mr. Posnack,

The Fenway Institute at Fenway Health and a coalition of 19 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 v4 posted in January, 2023. 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+, and about 5400 are transgender and nonbinary. About 2,300 of our patients are people living with HIV.

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 the agency's ongoing responsiveness to our priorities across multiple administrations. 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 Advisory (ISA) since the ISA was first published in 2015. SOGI standards have achieved steadily increasing and high levels of maturity and adoption since 2015, as reflected in the 2021

reference edition of the ISA (pages 43-45) and as evidenced by SOGI's inclusion in USCDI.[1,2]

Knowing a patient's current sexual orientation, gender identity, sex assigned at birth, name used, and pronouns, as well as their anatomical inventory, is important for informing clinical decision support, preventive screenings, and for managing health disparities at the population level.[3]

We welcome the opportunity to review and comment on the proposed USCDI v4. In USCDI v4, existing SOGI fields should be strengthened and expanded in order to increase the range of options for patients to self-identify using SOGI categories in their EHRs and other certified health IT products. This approach will maximize patient autonomy and will also provide maximum clinical benefit to patients and their healthcare providers.

Below we make recommendations about the display of SOGI fields in USCDI v4. It's important to note that every recommended field matches to an underlying SNOMED-CT code that is interoperable in HL7 v4/FHIR and is already in USCDI v3. This demonstrates the standards continuity between USCDI v3 and the changes in display of SOGI that we are asking ONC to make in USCDI v4.

We enthusiastically support adding response options, such as the term "nonbinary," as a gender identity field. At Fenway Health and with the 1400 FQHCs that we train to collect SOGI data through our National LGBTQIA+ Health Education Center, we encourage health centers to include this response option to the current gender identity question:

- Nonbinary, genderqueer, or not exclusively female or male

The "nonbinary" field could reference SNOMED-CT code 772004004, "Non-binary gender" finding.[4]

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[1] 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

[2] Office of the National Coordinator of Health Information Technology, US Core Data for Interoperability v3. January 2022. https://www.healthit.gov/isa/united-states-core-data-interoperability-uscdi#uscdi-v3

[3] 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

[4] https://browser.ihtsdotools.org/?perspective=full&conceptId1=772004004&edition=MAIN/SNOMEDCT-US/2023-03-01&release=&languages=en

Of Fenway Health's roughly 5400 transgender and gender diverse patients, about 1800—or one-third—identify as nonbinary. Many thousands of patients in FQHCs across the U.S. also identify as nonbinary. In the 2015 US Transgender Survey, 31% of the 27,715 transgender and gender diverse people surveyed said that they identified as nonbinary.[5] "Nonbinary" is a very common identity among gender diverse people in the U.S.

We encourage ONC to allow autonomy by individual health care organizations to use response options relevant to the patient populations they serve. The terms people use to identify themselves vary culturally and regionally. We recommend that ONC encourage organizations to maintain options such as "transgender male/man" and "transgender female/woman" (SNOMED-CT code 407377005). Many transgender people continue to identify as transgender men and transgender women, and don't want to have to choose between identifying as transgender and identifying as a man or woman. We see this with patients at Fenway Health and in FQHCs across the U.S. On the 2015 US Transgender Survey, 65% of respondents identified as transgender, 56% as trans, 32% as "trans woman (MTF, male to female)," and 31% as "trans man (FTM, female to male)."[6] The terms people use to identify themselves evolve over time and the USCDI infrastructure should support this evolution.

We also recommend that ONC create guidance for vendors and healthcare organizations to encourage them to no longer display the terms "Female-to-Male (FTM)" and "Male-to-Female (MTF)." Fenway Health stopped displaying these options in our EHR's gender identity response options, and we encourage other organizations to do the same in our training and technical assistance on how to collect and use SOGI data. The percentage of transgender people using these identities appears to have declined significantly, although some transgender patients still identify as FTM or MTF. These terms suggest a directionality instead of acknowledging the individual's gender. We think that the optimal approach is to display the terms "transgender man" and "transgender woman."

ONC should consider allowing for the selection of multiple gender identity categories. Until a multi-selector option is available, we recognize that some individuals identify with the term transgender and that the value set should allow for this option. Our full set of response options for the current gender identity

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[5] James, S. E., Herman, J. L., Rankin, S., Keisling, M., Mottet, L., & Anafi, M. (2016). *The Report of the 2015 U.S. Transgender Survey*. Washington, DC: National Center for Transgender Equality. Page 44.

[6] Ibid.

question, which encompasses patients across the age spectrum, is as follows. Each of these options corresponds to the SNOMED-CT code included in parentheses next to the term(s).

- ☐ Girl/woman/female (446141000124107)
- ☐ Boy/man/male (446151000124109)
- ☐ Nonbinary, genderqueer, or not exclusively female or male (772004004)
- ☐ Transgender woman/girl/female (407376001)
- ☐ Transgender man/boy/male (407377005)
- ☐ Another gender. Please specify:_____ (nullFlavor OTH)
- ☐ Don't know (questioning; do not understand) (nullFlavor ASKU)
- ☐ Prefer not to answer

This approach will maximize patients' ability to self-identify using the gender identity field while also updating the language in USCDIv4 to be more culturally competent. The ongoing slow and steady improvement and modulation of SOGI fields over time should be part of ONC's overall long-term SOGI strategy. This is particularly important for ONC to consider, because the individual and shared identity categories that are used within the LGBTQIA+ community consistently change over the course of decades.[7]

We applaud and support the efforts of Health Level Seven International (HL7)'s Gender Harmony Workgroup in establishing interoperability of name used, gender identity, sex for clinical use, recorded sex or gender, and pronouns.[8]

We encourage ONC to make clear that health care providers serving Indigenous patients, whether in urban 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, as per the recommendation in the recent National Academy of Sciences, Medicine and

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[7] Vogler, Stefan. *Sorting Sexualities: Expertise and the Politics of Legal Classification*. Chicago: The University of Chicago Press, 2021; Compton, D'Lane R., Tey Meadow, and Kristen Schilt, eds. *Other, Please Specify: Queer Methods in Sociology*. Oakland, California: University of California Press, 2018; D'Emilio, John. *Sexual Politics, Sexual Communities: The Making of a Homosexual Minority in the United States, 1940-1970*. Chicago: University of Chicago Press, 1983; Armstrong, Elizabeth A. *Forging Gay Identities: Organizing Sexuality in San Francisco, 1950-1994*. Chicago: University of Chicago Press, 2002.

[8] Robert C McClure, Caroline L Macumber, Clair Kronk, Chris Grasso, Robert J Horn, Roz Queen, Steven Posnack, Kelly Davison, Gender harmony: improved standards to support affirmative care of gender-marginalized people through inclusive gender and sex representation, *Journal of the American Medical Informatics Association*, Volume 29, Issue 2, February 2022, Pages 354–363, https://doi.org/10.1093/jamia/ocab196

Engineering (NASEM) report.[9] 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.

ONC should also consider adding a sex characteristics question to measure intersex status, or differences in sexual development. The Fenway Institute encourages ONC to work with LGBTQIA+ stakeholders, the intersex community and its leading organization interACT: Advocates for Intersex Youth, and health IT standards-setting entities such as SNOMED to develop interoperable health IT standards that reflect the categories used by intersex people to describe themselves. Researchers at the Fenway Institute are examining the best ways to ask patients about sex characteristics, working closely with intersex community leaders. Fenway would welcome an opportunity to connect ONC to intersex leaders and researchers to help develop culturally competent health IT standards to better serve members of the intersex community.

While we do recommend some slight modifications to existing displays of SOGI fields in USCDI, it is critical that ONC not remove any categories from the SO or GI fields in USCDI v4 until systems are capable of allowing for the selection of multiple gender identity options. Removing fields from existing SOGI standards would not only be potentially harmful from a patient care perspective, but also from a standards continuity perspective. Health IT developers should not be required to "unbuild" or remove SOGI fields that are currently present in certified Health IT systems. This could negatively affect patient health, particularly for patients who have provided their SOGI data in the past using current fields. It could also cause issues with regulatory continuity in regard to SOGI health IT standards development, and could be difficult for product developers to implement consistently.

As in previous comments to ONC, Fenway Health and our colleague organizations continue to support the inclusion of consent affordances for patients during instances of health information exchange and exchanges of patient data using interoperability standards, particularly during transfers of care. We believe that patients should be asked to *opt in* for data sharing of sensitive information, including sexual orientation, gender identity, and sex characteristics (SOGISC) data.

[9] 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.

Thank you for the opportunity to comment on USCDI v4. We greatly value the relationship with ONC that we have developed over the past 11 years, and appreciate your support of SOGI data collection to improve quality of care and to enhance LGBTQIA+ health equity. Should you have any questions, please contact Sean Cahill, PhD, Director of Health Policy Research, at scahill@fenwayhealth.org.

Sincerely,

The Fenway Institute
AIDS Action Baltimore
AIDS Foundation Chicago
AIDS United
Apicha Community Health Center
California LGBTQ Health and Human Services Network
Callen-Lorde Community Health Center
CenterLink: The Community of LGBTQ Centers
Equality Federation
Human Rights Campaign
The Lakes Community Health Center
Mazzoni Center
Minority Veterans of America
Movement Advancement Project
National Black Justice Coalition
National Center for Transgender Equality
National Health Law Program
National LGBT Cancer Network
Treatment Action Group
The Trevor Project