

April 30, 2022

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) v3

*Submitted electronically to <https://www.healthit.gov/isa/united-states-core-data-interoperability-uscdi#draft-uscdi-v3>*

Dear Dr. Tripathi and Mr. Posnack,

The Fenway Institute at Fenway Health and a coalition of 23 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 v3 posted in January, 2022. 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 appreciate that one of ONC's "top goals" in fostering health IT interoperability is "centering health equity."<sup>1</sup> 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

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<sup>1</sup> 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 (ISA) since the ISA was first published in 2015. SOGI standards have achieved steadily increasing and high levels of maturity and adoption since 2015,<sup>2</sup> as reflected in the 2021 reference edition of the ISA (pages 43-45) and as evidenced by SOGI's inclusion in USCDI v2.<sup>3</sup>

To this point, we are very grateful to ONC for including SOGI fields in USCDI v2 in July 2021. This critically important move is helping to expand SOGI data collection, use, exchange, and eventually seamless interoperability in health care to improve quality of care.

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 as well as understanding healthcare organization and population-level health disparities.<sup>4</sup> There are striking disparities in accessing preventive services that correlate with both 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. Discrimination in health care may cause sexual and gender minority patients to have higher rates of medical mistrust, which may constitute a barrier to accessing care.<sup>5</sup>

In addition to continuing to include SOGI data fields in sets of standards such as USCDI, it is especially important that clinical SOGI data collection and use be standardized and, at a minimum, encouraged, and even better, incentivized or required by ONC and other federal agencies such as the Centers for Medicare and Medicaid Services (CMS). Indeed, the Bureau of Primary Health Care (BPHC) within the Health Resources and Services Administration (HRSA) took this step proactively in 2016 by requiring Federally Qualified Health Centers (FQHCs) to

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<sup>2</sup> 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>

<sup>3</sup> 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>

<sup>4</sup> 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>

<sup>5</sup> Ahmed Mirza, Shabab and Rooney, Caitlin (2018). *Discrimination Prevents LGBTQ People from Accessing Health Care*. Washington, DC: Center for American Progress.

collect SOGI data report it in their annual Uniform Data System (UDS) reports.<sup>6</sup> In addition to improving the quality of patient care, access to greater amounts of SOGI data in high quality clinical datasets will increase collective understandings of SGM health disparities. For example, health systems will be able to use SOGI data in Quality Improvement (QI) initiatives and population health research that utilizes EHR 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, gender identity, assigned sex at birth, and pronouns.

The availability of data about assigned sex at birth, gender identity, 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.

We welcome the opportunity to review and comment on the proposed USCDI v3. Our comment is structured as requested in response to the three questions in ONC's call for public comment.

1. *Are there any improvements needed in the data classes or elements included in Draft USCDI v3, including:*
  - a. *Appropriate and meaningful data class and element names and definitions?*
  - b. *Representative examples or value sets used by health IT developers and implementers to fully understand the intent of the data element?*
2. *Should other data elements classified as Level 2 in the ONDEC system be added to USCDI v3 instead, or in addition to those in the Draft? If so, why?*
3. *Are there significant barriers to development, implementation or use for any of these data elements that warrant removing them from Draft USCDI v3?*

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<sup>6</sup> Health Resources and Services Administration (HRSA) Bureau of Primary Health Care (BPHC). "Program Assistance Letter: Approved Uniform Data System Changes for Calendar Year 2016 (PAL 2016-02)," March 22, 2016. <https://bphc.hrsa.gov/sites/default/files/bphc/datareporting/pdf/pal201602.pdf>.

We understand that ONC must strike a balance between having an expansive set of options for patients to self-identify and maintaining consistency and continuity in response options and data standards. In USCDIv3, 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.

In our 2015 comment to ONC about SOGI in the 2015 Base EHR Certification Criteria,<sup>7</sup> the Fenway Institute and the Center for American Progress (CAP) made very specific suggestions about which SNOMED CT codes should be used for each SOGI field in the 2015 Base EHR Certification Criteria, and how they should be displayed on-screen to be culturally competent. We were grateful when ONC included these fields in the 2015 Base EHR Certification Criteria, including the on-screen display specifications.<sup>8</sup> Then, in our 2018,<sup>9</sup> 2019,<sup>10</sup> and 2021<sup>11</sup> comments on USCDI v1 and USCDI v2, the Fenway Institute mainly recommended carrying over those 2015 Base EHR SOGI fields into USCDI, along with the revised on-screen display in certified health IT products. Again, we were grateful when the 2015 Base EHR SOGI fields were included in USCDIv2 in July 2021.<sup>12</sup>

Below we make recommendations about the display of SOGI fields in USCDI v3. 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 v2. This demonstrates the standards continuity between USCDI v2 and the changes in display of SOGI that we are asking ONC to make in USCDI v3.

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:

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<sup>7</sup> <https://fenwayhealth.org/wp-content/uploads/ONC-Health-IT-Certification-Criteria-rule-Fenway-CAP-public-comment-FINAL-052915.pdf>

<sup>8</sup> <https://fenwayhealth.org/wp-content/uploads/2015/10/SOGI-Press-Release1.pdf>

<sup>9</sup> <https://fenwayhealth.org/wp-content/uploads/USCDI-comment-Feb-2018.pdf>

<sup>10</sup> <https://fenwayhealth.org/wp-content/uploads/Fenway-Institute-ONC-21-century-cures-act-sign-on-comment.pdf>

<sup>11</sup> [https://fenwayhealth.org/wp-content/uploads/USCDI\\_Fenway\\_Comment\\_V2\\_041521.pdf](https://fenwayhealth.org/wp-content/uploads/USCDI_Fenway_Comment_V2_041521.pdf)

<sup>12</sup> <https://www.hhs.gov/about/news/2021/07/09/hhs-updates-interoperability-standards-to-support-electronic-exchange-of-sogi-sdoh.html>

- Nonbinary, genderqueer, or not exclusively female or male

The current response option, first adopted in 2015 and included in USCDI v2, reads:

- Genderqueer, neither exclusively male nor female, 446131000124102

The “nonbinary” field could reference SNOMED-CT code 772004004, “Non-binary gender” finding. This code is from the international edition of SNOMED-CT, not the U.S. edition. The current SNOMED-CT code that matches to “Genderqueer, neither exclusively male nor female” is 446131000124102, “Identifies as non-conforming gender.” While this language was current in 2015, “non-conforming gender” is pejorative and no longer used. We therefore recommend that ONC reference SNOMED-CT code 772004004, “Non-binary gender” finding to accompany a display of “Nonbinary, genderqueer, or not exclusively female or male.”

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.<sup>13</sup> “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).”<sup>14</sup> The terms people use to identify themselves evolve over time and the USCDI infrastructure should support this evolution.

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<sup>13</sup> 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.

<sup>14</sup> Ibid.

We also recommend that ONC create guidance for vendors and healthcare organizations 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 the value set should allow for this option. Our full set of response options for the current gender identity 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 (446131000124102)
- 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 USCDIV3 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.<sup>15</sup>

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.<sup>16</sup>

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 Engineering (NASEM) report.<sup>17</sup> 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. Researchers at the Fenway Institute are currently testing a question with patients, working closely with intersex community leaders. We would be happy to share thoughts about how to ask this question in an educational meeting with ONC staff, at an ONC Annual Meeting, or via a different modality. If there are not standards available to include these fields in USCDI v3, ONC can work with stakeholders to develop appropriate standards for inclusion in future versions of USCDI, and Fenway is ready to help ONC and others to develop those standards. Please also see our comment on the Standards Version Advancement Process (SVAP) in regard to the development of next-generation SOGI standards and writing them into US federal health IT policy. In our SVAP comment we delve more deeply into related issues, such as the importance of displaying pronouns and name used, which may not match the sex and name on a patient's insurance.

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<sup>15</sup> 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.

<sup>16</sup> 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>

<sup>17</sup> 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>.

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 v3 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. Fenway is engaged with the multi-stakeholder Protecting Privacy to Promote Interoperability (PP2PI) workgroup. PP2PI is working to develop use-cases that account for these issues and which are aimed at better operationalizing the information blocking exceptions in the 21<sup>st</sup> Century Cures Act final rule, and otherwise maximizing patients’ ability to consent to data re-uses and exchanges of their data. Our basic position is that patients should be asked to *opt in* for data sharing of sensitive information, including sexual orientation, gender identity, and sex characteristics (SOGISC) data.

Thank you for the opportunity to comment on USCDI v3. We greatly value the relationship with ONC that we have developed over the past decade, and appreciate your support of SOGI data collection to improve quality of care and enhance LGBTQIA+ health equity. Should you have any questions, please contact Sean Cahill, PhD, Director of Health Policy Research at the Fenway Institute, at [scahill@fenwayhealth.org](mailto:scahill@fenwayhealth.org).

Sincerely,

The Fenway Institute  
AIDS Action Baltimore  
AIDS Alabama South  
Callen-Lorde Community Health Center

Center for LGBTQ Economic Advancement and Research (CLEAR)  
Community Healthcare Network  
GLMA: Health Professionals Advancing LGBTQ Equality  
HealthHIV  
HIV Medicine Association  
interACT: Advocates for Intersex Youth  
Legacy Community Health  
Lyon-Martin Community Health Services  
Movement Advancement Project  
NASTAD  
National LGBT Cancer Network  
North Carolina AIDS Action Network  
NorthLakes Community Clinic  
SAGE  
The National Coalition for LGBTQ Health  
The Trevor Project  
Thrive Alabama  
Transgender Law Center  
Transhealth Northhampton  
Treatment Action Group