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Dr. Karen DeSalvo
National Coordinator for Health Information Technology
Department of Health and Human Services
Attention: Interoperability Standards Advisory Public Comments
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Public Comment on draft *Interoperability Standards Advisory* released January 28, 2015

Submitted by the Fenway Institute, the Center for American Progress, the Mayo Clinic, the Los Angeles LGBT Center, and several other health care, research, professional, and patient advocacy organizations

Dear Dr. DeSalvo:

We write to comment on the draft *2015 Interoperability Standards Advisory*, released by ONC on January 28, 2015. We welcome ONC's initiation of an interactive process and dialogue to develop standards and implementation specifications for a broad range of clinical health IT interoperability purposes.

As health care providers, researchers, educators, and advocates focusing on the health of lesbian, gay, bisexual, and transgender (LGBT) communities, we are especially pleased to see that codes for sexual orientation and gender identity (SO/GI) data are included in the draft implementation specifications. In order to substantively advance the goals of the Meaningful Use program and optimize the utility of these data, however, several changes and clarifications are needed. In particular, while the proposed SNOMED CT SO/GI codes are technically functional, they reflect outdated and, for some individuals, offensive terminology that may interfere with the goal of providing welcoming and affirming health care to LGBT individuals.

We therefore recommend that ONC work with the National Library of Medicine (NLM) to develop alternate SNOMED CT codes that better reflect the lives and identities of LGBT individuals. (Some of the groups signed onto this comment also plan to submit requests for changes to SNOMED CT following the established process to the NLM.) We further recommend that all ONC rulemaking on electronic health records, including but not limited to the interoperability standards and the proposed certification criteria for Meaningful Use Stage 3, require certified EHR systems to show all front-end users, such as health care providers, staff, and patients, a single standard set of questions and answers with appropriate language around concepts related to SO/GI, regardless of the wording of the codes that the answers map onto in the underlying EHR architecture. These questions should be 1) sexual orientation, 2) gender identity, and 3) assigned sex. Below we discuss these recommendations in more detail.

SNOMED CT codes

The draft *Interoperability Standards Advisory* describes SNOMED CT codes as the “[b]est available Vocabulary/Code Set/Terminology Standards and Implementation Specifications” for sexual orientation and gender identity (pp. 6-7). According to the Meaningful Use Stage 3 proposed rule, these codes are as follows:

Sexual orientation:

- Homosexual SNOMED CT® 38628009
- Heterosexual SNOMED CT® 20430005
- Bisexual SNOMED CT® 42035005
- Other HL7 V3 nullFlavor OTH
- Asked but unknown .. HL7 V3 nullFlavor ASKU
- Unknown HL7 V3 nullFlavor UNK

Gender identity:

- Identifies as male gender. SNOMED CT®446151000124109*
- Identifies as female gender. SNOMED CT® 446141000124107*
- Female-to-male transsexual. SNOMED CT® 407377005
- Male-to-female transsexual. SNOMED CT® 407376001
- Identifies as non-conforming gender. SNOMED CT® 446131000124102*
- Other HL7 V3 nullFlavor OTH
- Asked but unknown .. HL7 V3 nullFlavor ASKU

While these codes for sexual orientation and gender identity have some technical functionality, they are suboptimal. Terms such as “homosexual” and “transsexual” are sometimes used to describe minority sexual orientation and gender identity, but many LGBT people themselves dislike these terms, considering them outdated and stigmatizing. Collecting SO/GI data in EHRs offers the opportunity for LGBT patients and their providers to form a positive therapeutic relationship based on trust, but this opportunity will not be realized if the language used to ask these questions is fundamentally off-putting.

We therefore recommend that ONC work with the NLM to create the following SNOMED CT codes and allow them to be used as synonyms for the existing SNOMED codes that are problematic:

- Instead of “homosexual”: “gay” and “lesbian”
- Instead of “female-to-male transsexual”: “transgender man”
- Instead of “male-to-female transsexual”: “transgender woman”

Recommended questions and answers for sexual orientation and gender identity

In order to streamline SO/GI data collection in clinical settings and to promote a common understanding among clinical staff of how to gather these data in a respectful way that promotes trusting and open dialogue with LGBT patients, we recommend that ONC incorporate the following standard questions and answer options into all rulemaking and other guidance on the Meaningful Use program, including the interoperability standards. These questions and answers are based on research conducted in a diverse set of community health centers across the United States,¹ as well as current surveillance and other public health activities conducted by the Centers for Disease Control and Prevention. We have noted below in italics how these standard answer choices should be understood to relate to the existing SNOMED CT and HL7 codes in the Meaningful Use Stage 3 proposed rule:

1. Do you think of yourself as:
 - a. Straight or heterosexual (*SNOMED CT code: "heterosexual"*)
 - b. Lesbian, gay, or homosexual (*SNOMED CT code: "homosexual," but create new SNOMED codes for "gay" and "lesbian" and allow them as synonyms*)
 - c. Bisexual (*SNOMED CT code: "bisexual"*)
 - d. Something else, please describe _____ (*HL7 code "other"*)
 - e. Don't know (*HL7 code "asked but unknown"*)

2. What is your current gender identity? (Check all that apply.)
 - a. Male (*SNOMED CT code "identifies as male gender"*)
 - b. Female (*SNOMED CT code "identifies as female gender"*)
 - c. Transgender male/Trans man/Female-to-male (*SNOMED CT code "female-to-male transsexual," but create new SNOMED code for "transgender man" and allow as a synonym*)
 - d. Transgender female/Trans woman/Male-to-female (*SNOMED CT code "male-to-female transsexual," but create new SNOMED code for "transgender woman" and allow as a synonym*)
 - e. Genderqueer, neither exclusively male nor female (*SNOMED CT code "identifies as non-conforming gender"*)
 - f. Additional gender category/(or other), please specify _____ (*HL7 code "other"*)
 - g. Decline to answer (*HL7 code "asked but unknown"*)

In line with the tested and recommended SO/GI question designs,² a field for "assigned sex at birth" should be added to the draft interoperability standards and asked immediately after the "current gender identity" question. This will allow for the identification of a patient as transgender through data indicating that the individual's assigned sex is different from the individual's current gender identity. For example, a transgender woman may identify her current gender identity as "female" ("identifies as female gender") and indicate that the sex she was assigned at birth is "male." We recommend the following assigned sex at birth question and answer options.

3. What sex were you assigned at birth on your original birth certificate? (Check one.)
 - a. Male (*SNOMED CT code "male" 248153007*)
 - b. Female (*SNOMED CT code "female" 248152002*)
 - c. Decline to answer (*HL7 code "asked but unknown"*)

Documentation of both assigned sex at birth and current gender identity is critical for delivering appropriate care to transgender patients. **We strongly caution that current gender identity data must be the information that populates the “gender” field on patient identification materials, such as hospital wristbands, and that should be used for purposes such as determining the gender pronouns used to communicate with patients and making room assignments.** Assigned sex at birth data should be used for clinical decision support on the basis of the patient’s anatomy. The “sex” data that the draft interoperability standards propose to code using the HL7 codes for “administrative gender” are separate and distinct from assigned sex at birth, and should be used only as necessary, e.g. for insurance billing purposes, not for identifying, housing, or communicating with patients.

As an example, again consider a transgender woman. The relevant data in the record would be:

- Current gender identity: SNOMED code “identifies as female gender” or “transgender woman”
- Assigned sex at birth: SNOMED code “male”
- “Sex”/Administrative gender: preferentially HL7 code “female,” but possibly “male” depending on issues such as difficulty billing insurance for traditionally “male” services such as a prostate exam.

Regardless of the data in the administrative gender field, this individual should be referred to as “she” and “her” throughout her time in the clinical setting, in accordance with her current gender identity. Similarly, identification such as a wristband should indicate her sex as “female,” and in sex-segregated circumstances such as room assignments, she should be housed according to her female gender identity.

We commend ONC for including sexual orientation and gender identity in the draft *Interoperability Standards Advisory*. We encourage ONC to take the necessary steps to work with the NLM on improving the existing SNOMED CT codes and to use this opportunity to institute adoption of a single standard of SO/GI questions and answers that were developed with LGBT community input and validated in peer-reviewed research.

We thank you for your time and attention to this matter and look forward to continuing to work with the Office of the National Coordinator to improve data collection in EHRs and increase health information exchange to improve health outcomes for all patients, including LGBT people. Should you have any questions, please contact Sean Cahill at scahill@fenwayhealth.org, or at 617-927-6016.

Sincerely Yours,

Fenway Institute, Fenway Health

Center for American Progress

AIDS United

Center for HIV/AIDS Research, Education, and Policy
Myrlie Evers-Williams Institute for Elimination of Health Disparities

University of Mississippi Medical Center
Jackson, MS

GLMA: Health Professionals Advancing LGBT Equality (formerly Gay and Lesbian Medical Association)

HIV Medicine Association

Los Angeles LGBT Center

Mayo Clinic

Open Arms Healthcare Center
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¹ Cahill, S., R. Singal, C. Grasso et al. 2014. "Do Ask, Do Tell: High Levels of Acceptability by Patients of Routine Collection of Sexual Orientation and Gender Identity Data in Four Diverse American Community Health Centers." *PLOS One* 9(9). doi:10.1371/journal.pone.0107104.

² Ibid.