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Dr. Karen DeSalvo

National Coordinator for Health Information Technology

Attention: 2015 Edition Health IT Certification Criteria Proposed Rule

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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

Submitted by the Fenway Institute, the Center for American Progress, and 103 other health care, research, professional, and patient advocacy organizations

Dear Dr. DeSalvo:

We write to comment on the 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. As health care providers, researchers, educators, and advocates focusing on the health of lesbian, gay, bisexual, and transgender (LGBT) communities, we are pleased to see ONC's proposal to include sexual orientation and gender identity (SO/GI) functionality in a Health IT module as part of the EHR certification criterion:

We propose to require that a Health IT Module enable a user to record, change, and access a patient's sexual orientation and gender identity as part of this certification criterion...[list of SNOMED CT codes for SO/GI]...We note that the functionality under consideration to record the data discussed above has no bearing on whether a patient chooses to provide this information or whether a health care provider chooses to record the information or would be required to do so through the EHR Incentive Programs or other programs (pp. 87-89).

Our enthusiasm is tempered, however, by the fact that the proposed rule would include SO/GI fields in an optional social, psychological, and behavioral data module, and not as part of the Demographics criterion (as included in the Base EHR definition), or as part of the Common Clinical Data Set. **If SO/GI functionality is optional for vendor certification, then few EHR vendors will include these fields, and SO/GI data are less likely to be collected and used by providers to evaluate the quality of care provided to LGBT people. As a result, the ability to track SO/GI in EHRs will not become an industry standard. This is a major missed opportunity.**

Sexual orientation and gender identity should be required in the Demographics criterion (as included in the Base EHR definition) and in the Common Clinical Data Set

We strongly urge ONC to make SO/GI fields part of the base EHR certification requirements by including them as part of the Demographics criterion that all EHRs must be able to track. Sexual orientation and gender identity are important aspects of a patient's identity and relevant to clinical care. This is true, for example, in clinical decision support. Transgender women who were assigned the male sex at birth should be offered a prostate exam as appropriate. Gay and bisexual men and transgender women should be regularly tested for HIV, syphilis, and other STIs. Inclusion of SO/GI in the Demographics criterion (as included in the Base EHR definition) would improve care through more appropriate clinical decision tailored to SO/GI, and allow for identification and analysis of LGBT health disparities via the creation of patient lists that can track SO/GI. Moreover, if ONC adds SO/GI fields to the Clinical Quality Measures (CQM) filtering criterion, one could likewise identify disparities by filtering CQM results by SO/GI.

We also urge ONC to include SO/GI in the Common Clinical Data Set. As noted above, knowledge of a patient's sexual orientation or gender identity can be an important part of treatment. Inclusion of SO/GI in the Common Clinical Data Set would facilitate its exchange among providers during transitions of care and referrals, as well as its availability to patients and authorized representatives via view/download/transmit.

Requiring that EHRs certified for use under the Meaningful Use program include SO/GI functionality would incentivize vendors to include such functionality in EHR software, and help to make it the industry norm. These are all important steps that will make it easier for providers to track SO/GI data on patients in their EHRs, a critical step toward documenting, addressing and reducing LGBT health disparities in preventive screenings, risk behaviors, disease burden, and health outcomes.

Proposed terminology

In order to substantively advance the goals of the Meaningful Use program and optimize the utility of these data, several other changes and clarifications are needed in addition to making inclusion of SO/GI fields a certification requirement for EHRs. While the SNOMED CT SO/GI codes described in the proposed rule 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 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.

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,” “trans male,” and “transgender female-to-male”
- Instead of “male-to-female transsexual”: “transgender woman,” “trans female,” and “transgender male-to-female”

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. 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, **not sex assigned at birth**, 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 facilitates identification of organs that may be present and require preventive screenings (see, e.g., Deutsch MB, Green J, Keatley JA, *et al.*, Electronic medical records and the transgender patient: recommendations from the World Professional Association for Transgender Health EMR Working Group, *J Am Med Inform Assoc*, 2013. doi:10.1136/amiajnl-2012-001472). We note that, since we submitted comments on the draft interoperability standards on May 1, 2015, HHS has issued guidance clarifying that health plans must cover all anatomically appropriate preventive screenings for transgender individuals.³

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”

This individual should be referred to as “she” and “her” throughout her time in the clinical setting, in accordance with her current gender identity. To facilitate the use of the correct name and pronoun in all views (such as banner, schedule, auto-populated text within progress notes), the EHR should be able to record preferred gender pronoun as well as “alias” or “preferred name.” Recording of preferred gender pronoun could look like:

Preferred gender pronoun:

- *He/Him*
- *She/Her*
- *They/Them*

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. If an administrative gender field is present, it should read “female” in HL7 or whatever code set is being used to capture administrative gender.

Summary

We commend ONC for including sexual orientation and gender identity in the 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. **We strongly urge ONC to 1) require SO/GI functionality as part of the Demographics criterion (as included in the Base EHR definition) for the 2015 Edition Health IT Certification, and 2) require SO/GI functionality as part of the Common Clinical Data Set. Making SO/GI functionality optional through the proposed inclusion in the social, psychological and behavioral module would represent an unfortunate half measure that will cause few EHR vendors to include SO/GI fields in their software.**

By including SO/GI in both the Demographics criterion and the Common Clinical Data Set, the federal government would enable the identification and reduction of LGBT health disparities in a variety of scenarios. As a component of the Demographics criterion, SO/GI data could be utilized as a variable in

other certification criteria that work to identify health disparities and gaps in care—namely the creation of patient lists and Clinical Quality Measure results filtering, if modified as proposed above. Moreover, inclusion in the Common Clinical Data Set is essential because SO/GI data would be exchanged in transitions of care and shared with patients through the view/download/transmit function.

We also encourage ONC to work with the NLM to improve the proposed 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. We look forward to continuing to work with the Office of the National Coordinator and CMS to improve SO/GI data collection in EHRs to better understand and reduce LGBT health disparities. Should you have any questions, please contact Harvey Makadon, M.D., Director of Education and Training at the Fenway Institute, at hmakadon@fenwayhealth.org, or at 617-927-6426.

Sincerely Yours,

Fenway Institute

Center for American Progress

ACRIA

Adelante Health Care, Phoenix

AIDS Foundation of Chicago

AIDS United

amfAR

APICHA Community Health Center, New York

Athlete Ally

BAGLY, Inc. (Boston Alliance of LGBTQ Youth)

Basic Rights Oregon

Beth Israel Deaconess Medical Center, Boston

Boston University School of Public Health

Brigham and Women's Faulkner Hospital, Boston

Brigham and Women's HealthCare, Boston

California Lesbian, Gay, Bisexual, and Transgender Health and Human Services Network

Callen-Lorde Community Health Center, New York

Campus Pride

Center for Health Law and Policy Innovation, Harvard Law School

Center for HIV/AIDS Research, Education, and Policy

Myrlie Evers-Williams Institute for the Elimination of Health Disparities

University of Mississippi Medical Center, Jackson

Center of Excellence for Transgender Health, University of California San Francisco

CenterLink: The Community of LGBT Centers

Chase Brexton Health Care Services, Maryland

Coalition for Disability Health Equity

Community Access National Network (CANN)

Contra Costa Health Services

Disability Policy Consortium, Boston

Empire State Pride Agenda

Equality California

Equality Federation

Equality Illinois

Equality Maryland

Equality New Mexico

Equality Ohio

Equality Virginia

Equality Maine

Fair Wisconsin

Family Equality Council

Fenway Health, Boston

FORGE, Inc., Milwaukee

Garden State Equality

Gay & Lesbian Advocates & Defenders, Boston

Gay Men's Health Crisis (GMHC), New York

Gender Health Center, Sacramento

Gender Justice League, Seattle

Georgia Equality

GLMA: Health Professionals Advancing LGBT Equality

Harrington Park Press, LLC

HIV Medicine Association

Howard Brown Health Center, Chicago

Human Rights Campaign

Justice Resource Institute, Boston

Lambda Legal

Latino Commission on AIDS

Latinos Salud, Florida

League of United Latin American Citizens

Legacy Community Health, Houston

Lesbian Health Initiative (LHI), Houston

Lesbian, Gay, Bisexual & Transgender Community Center, New York City

LGBT Primary Care Alliance

Los Angeles LGBT Center

Marriage Equality USA

Maryland Citizens' Health Initiative Education Fund, Inc.

Massachusetts General Hospital

MassEquality

Mayo Clinic

Mazzoni Center, Philadelphia

Metro Community Provider Network, Inc., Englewood, Colorado

Minnesota Trans Health Coalition

Multicultural AIDS Coalition, Inc., Boston

NAACP

National Alliance of State & Territorial AIDS Directors

National Association of Community Health Centers

National Black Gay Men's Advocacy Coalition

National Black Justice Coalition

National Center for Transgender Equality

National Coalition for LGBT Health

National Coalition of STD Directors (NCSD)

National LGBTQ Task Force

National Network of STD Prevention Clinical Training Centers

National Network of STD/HIV Prevention Training Centers

National Partnership for Women & Families

New Jersey Citizen Action

One Colorado Education Fund

Open Arms Healthcare Center, Jackson, Mississippi

Our Family Coalition, San Francisco

OutFront Minnesota

Partners Healthcare System, Boston

PFLAG National

Planned Parenthood Federation of America and Planned Parenthood Action Fund

Project Inform

Rainbow Health Initiative, Minneapolis

SAGE (Services and Advocacy for GLBT Elders)

San Francisco AIDS Foundation

Sidney Borum Jr. Health Center, Boston

Southern Arizona Gender Alliance

The LGBT Health Resource Center of Chase Brexton Health Care, Maryland

The Montrose Center, Houston

The National LGBTQ Task Force

The Williams Institute, UCLA School of Law

Transgender Education Network of Texas

Trillium Health, Rochester, New York

Trust for America's Health

University of California, Davis Health System

Young Invincibles

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¹ Cahill S, Singal R, Grasso C, King D, Mayer K, Baker K, Makadon H. 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.

³ http://www.cms.gov/CCIIO/Resources/Fact-Sheets-and-FAQs/Downloads/aca_implementation_faqs26.pdf (see Q5).