

April 28, 2014

Submitted electronically

Office of the National Coordinator for Health Information Technology
Department of Health and Human Services
Attention: 2015 Edition EHR Standards and Certification Criteria Proposed Rule
Hubert H. Humphrey Building, Suite 729D
200 Independence Ave, S.W.
Washington, D.C. 20201

Public Comment on Notice of Proposed Rule Making, RIN 0991-AB92, the Voluntary 2015 Edition Electronic Health Record Certification Criteria; Interoperability Updates and Regulatory Improvements, including 2017 Certified EHR Technology (CEHRT) proposals

<https://www.federalregister.gov/articles/2014/03/19/2014-06041/voluntary-2015-edition-electronic-health-record-ehr-certification-criteria-interoperability-updates>

Submitted by the Fenway Institute, the Center for American Progress, and **X** other organizations

Dear Dr. DeSalvo:

We appreciate the Office of the National Coordinator for Health Information Technology (ONC) utilizing the proposed Voluntary 2015 Edition Electronic Health Record (EHR) Certification Criteria to signal its intent to include sexual orientation and gender identity (SO/GI) in the 2017 Edition Certified EHR Technology (CEHRT). A growing body of research and policy analysis indicates that collecting these data is an important aspect of providing optimal care for diverse populations, particularly with regard to advancing patient-centered care for the lesbian, gay, bisexual, and transgender (LGBT) population.¹

We strongly agree with ONC's suggestion to move forward with collecting SO/GI data as part of ensuring that the Meaningful Use program maximally meets the needs of patients and providers. However, we note that ONC has proposed to achieve SO/GI data collection as part of the certification criteria by incorporating a code set for sexual orientation contained in the SNOMED-CT vocabulary and a suggested SNOMED-CT code set for gender identity put forward by HL7.² On the basis of our many years of aggregate experience as clinicians, health data

¹ See, e.g., The Joint Commission. (October 2011). *Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care for the Lesbian, Gay, Bisexual, and Transgender Community: A Field Guide*. http://www.jointcommission.org/assets/1/18/LGBTFieldGuide_WEB_LINKED_VER.pdf

The Institute of Medicine. (October 2012). *Collecting Sexual Orientation and Gender Identity Data in Electronic Health Records: Workshop Summary*. http://books.nap.edu/openbook.php?record_id=18260

² The proposed code sets are as follows:

- Sexual orientation: *asexual; bisexual; gay; heterosexual; lesbian; questioning (a person who is questioning his/her sexual orientation); decline to answer; and not applicable (ages 0-17)*
- Gender identity: *Gender variant; man; intersex; questioning (a person who is questioning his or her sexual orientation); transgender; woman; decline to answer; and not applicable (ages 0-17)*

stewards, and researchers working with the LGBT population, we are concerned that the proposed code sets are inappropriate in their use of terminology and concepts that do not accurately reflect the realities of patients' lives and identities.

To facilitate the effective and accurate collection of SO/GI data, we recommend that ONC request the National Library of Medicine to develop new codes that reflect SO/GI data as captured in questions that have been shown to work effectively in clinical settings. In 2013, the Fenway Institute tested SO/GI questions in four community health centers in South Carolina, Maryland, Illinois, and Massachusetts.³ The health centers are in a mix of rural and urban settings, and the patient sample (n=301) was predominantly heterosexual, non-transgender, racially diverse, and included almost 10% of respondents in the over-65 age group. Among the patients we surveyed about these questions, overwhelming majorities across all demographic groups understood the questions, answered them, and think it is important for health care providers to know their sexual orientation and gender identity. In particular, the LGBT patients who answered these questions strongly agreed that the option choices allowed them to accurately report their sexual orientation and gender identity. On the basis of this research, we encourage ONC to move forward with including the following SO/GI data concepts in the 2017 Edition, as well as in future CEHRT editions:

Sexual orientation:

Do you think of yourself as:

- Lesbian, gay or homosexual
- Straight or heterosexual
- Bisexual
- Something else, please describe: _____
- Don't know

Gender identity:

With regard to gender identity, it is important to note that many transgender people do not identify as transgender. For example, a person who was born male, but whose current gender identity is female, may choose "female" rather than "transgender." By asking about sex assigned at birth as well as current gender identity, we will get better, more clinically relevant data, and have a clearer picture of the patient's identity and clinical needs. As such, gender identity data collection should involve both of the following concepts:

What is your current gender identity? (Check all that apply)

- Male

³ Cahill S., Singal R., Grasso C., King D., Mayer K., Baker K., Makadon H. (2013, December 18). *Asking patients questions about sexual orientation and gender identity in clinical settings: A study in four health centers*. The Fenway Institute and the Center for American Progress.
http://thefenwayinstitute.org/wp-content/uploads/COM228_SOGI_CHARN_WhitePaper.pdf.

- Female
- Female-to-Male (FTM)/Transgender Male/Trans Man
- Male-to-Female (MTF)/Transgender Female/Trans Woman
- Genderqueer, neither exclusively male nor female
- Additional Gender Category/(or Other), please specify _____
- Decline to answer

What sex were you assigned at birth on your original birth certificate? (Check one)

- Male
- Female
- Decline to answer

We suggest adding a response option of “Other” to the question regarding sex assigned at birth, to reflect the fact that some intersex individuals may not be labeled at birth as either male or female.

We also suggest adding two additional questions to prevent misunderstandings that may occur for transgender people who do not have identification documents that accurately reflect their current name and gender identity:

Preferred gender pronoun:

- He/Him
- She/Her
- Something else (Specify:_____)

Preferred name: (Specify:_____)

Preferred name and gender pronoun information has been shown to greatly facilitate patient-centered communication in clinical settings when coupled with appropriate staff training.

We believe capturing SO/GI data as reflected in the tested questions presented above will substantially promote the effectiveness, acceptability to patients, and clinical utility of collecting these data. 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 achieve the goals of the Meaningful Use program.

Sincerely Yours,

The Fenway Institute
 The Center for American Progress
 [List in formation]