

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 151 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

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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

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 stewards, researchers, and others 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: _____

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)*

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.

- 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
- 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 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.

The NPRM notes that “concerns have been raised about the need to balance privacy and security with data flow needs.” Given the stigma and discrimination that many LGBT people experience, these are important concerns. We acknowledge the potential sensitivity of these data and the need to train staff in how to gather these data in a culturally appropriate way while safeguarding patient privacy and confidentiality. However, as institutions such as the National Institutes for Standards and Technology continue to develop standards for encoding medical information, along with best practices for how to manage a computer infrastructure, the potential risks to privacy and security posed by SO/GI data collection are manageable and no greater than those posed by the collection of any other personal information, particularly in the intimacy of health care settings.⁴ Further, a 2012 federal regulation mandates “appropriate security and privacy protections” for any “personally identifiable information,” including sensitive health information that is collected and used in the provision of health care.⁵

Another concern is whether self-disclosure may expose LGBT patients to discrimination by providers and clinical staff in states without nondiscrimination laws. While 29 states lack sexual orientation nondiscrimination laws and 33 lack gender identity nondiscrimination laws, the sex nondiscrimination provision in Section 1557 of the Affordable Care Act prohibits discrimination on the basis of gender identity and sex stereotyping by any provider, facility, or program receiving federal funds, and current jurisprudence is moving in the direction of explicitly recognizing sexual orientation as a protected category as well.⁵ The Joint Commission’s 2011 *Comprehensive Accreditation Manual for Hospitals* requirement that hospitals adopt sexual orientation and gender identity nondiscrimination policies is another important step toward reducing anti-LGBT discrimination in health care.⁶

Finally, it is important to note that disclosing SO/GI information – like any demographic data – is voluntary for all patients. While we acknowledge the concerns raised in the NPRM about privacy and security, we believe that these can be addressed and that the benefits of gathering SO/GI data to improve patient care and improve understanding of LGBT health disparities substantially outweigh these risks.

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

⁴ Gupta, A. Hackers, breaches and other threats to electronic records. *Health Data Management*. 2011; 19: 54.

⁵ See, e.g., *Terveer v. Billington* (2014), finding that discrimination on the basis of sexual orientation is prohibited under the sex nondiscrimination protections in Title VII of the Civil Rights Act of 1964, which are analogous to the sex nondiscrimination protections in ACA Section 1557.

⁶ Rights and Responsibilities of the Individual (RI) element of performance 28.

goals of the Meaningful Use program. Should you have any questions, please contact Sean Cahill at scahill@fenwayhealth.org, or at 617-927-6016.

Sincerely Yours,

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Aging Studies Institute, Syracuse University
AID Gwinnett / Ric Crawford Clinic
AIDS Foundation of Chicago
AIDS Resource Center of Wisconsin
AIDS United
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Aqua Foundation for Women (Miami, FL)
Association for Family and Community Integrity Inc (Houston, TX)
Black AIDS Institute
Boston Alliance of GLBT Youth
California Breast Cancer Research Program
California LGBT Health & Human Services Network
Callen-Lorde Community Health Center
Campaign for Better Health Care, Illinois
Campus Pride
Center for Black Equity, Inc.
CenterLink: The Community of LGBT Centers
Central City AIDS Network (Macon, GA)
Chicago Women's AIDS Project
Christie's Place (San Diego)
Colorado AIDS Project
Colorado Consumer Health Initiative
Community Access National Network (CANN)
Community Healthcare Network, NYC
Empire State Pride Agenda
Equality California
Equality Federation
Equality Florida Institute, Inc.
Equality Maryland
Equality Texas
Family Equality Council
FORGE, Inc.
Gay-Straight Alliance Network
Gay and Lesbian Advocates and Defenders

Gender Health Center (Sacramento, CA)
Georgia Equality
Georgia Rural Urban Summit
GLMA: Health Professionals Advancing LGBT Equality
GMHC (Gay Men's Health Crisis)
GNP+NA
Harlem United Community AIDS Center
Harvard Law School Center for Health Law & Policy Innovation
HealthHIV
HIV Medicine Association
HIV Prevention Justice Alliance
House of Blahnik, Inc.
Housing Assistance Payments Initiative, (HAPI) Housing Program
Housing Works
Howard Brown Health Center
Illinois Caucus for Adolescent Health
JSI Research & Training Institute, Inc.
Justice Resource Institute
Juxtaposed Center 4 Transformation, Inc.
L.A. Gay & Lesbian Center
Lambda Legal
Latino Commission on AIDS
Latino Equality Alliance
Latinos Salud
League of United Latin American Citizens
Legacy Community Health Services
Lesbian Health & Research Center at UCSF
Lesbian Health Initiative of Houston, Inc.
LGBT Physician Assistant Caucus of the American Academy of Physician Assistants, Inc.
Lesbian, Gay, Bisexual & Transgender Community Center
LGBT Center of SE Wisconsin
LGBT Health Policy & Practice Program at George Washington University
LGBT Health Services, Mount Sinai Health System
Lyon-Martin Health Services
Maryland Citizens' Health Initiative Education Fund, Inc.
Maryland Women's Coalition for Health Care Reform
Massachusetts Commission on LGBTQ Youth
Massachusetts Department of Public Health
MassEquality.org
Mayo Clinic
Mazzoni Center
Metro Community Provider Network, Inc.,
Michigan Consumers for Healthcare
Global Forum on Men who have Sex with Men and HIV
Mt. Baker Planned Parenthood (Washington state)
Multicultural AIDS Coalition, Inc.
National Alliance of State & Territorial AIDS Directors

National Association of Social Workers
National Black Justice Coalition
National Center for Lesbian Rights
National Coalition for LGBT Health
National Center for Transgender Equality
National Coalition of STD Directors
National Council of Jewish Women
National Gay and Lesbian Task Force
National Health Law Program
National Latina Institute for Reproductive Health
National LGBT Cancer Network
National Minority AIDS Council
National Partnership for Women & Families
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New Jersey Citizen Action
New Voices Pittsburgh
North End Waterfront Health (Boston)
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Open Arms Healthcare Center (Jackson, MS)
Oregon Foundation for Reproductive Health
Organization for Transgender Health Empowerment Resources (OTHER)
OutFront Minnesota
PFLAG National
Planned Parenthood Mid and South Michigan
Planned Parenthood of the Rocky Mountains
Positively Healthy
PRIDE Clinic at MetroHealth Medical Center (Cleveland)
Pride Foundation
Project Inform
PROMO
Queer Humboldt
Rainbow Health Initiative (Minneapolis)
Raising Women's Voices for the Health Care We Need (RWV)
Resource Center (Dallas)
Rockway Institute for LGBT Research & Public Policy, Alliant International University
San Francisco Dept. of Public Health Bridge HIV (for identification only)
San Francisco AIDS Foundation
San Francisco Community Clinic Consortium
SAVE Dade
Services and Advocacy for GLBT Elders (SAGE)
Sidney Borum Health Center/Fenway Health
Society for the Psychological Study of LGBT Issues (Division 44 of the American Psychological Association)
Southern Arizona Gender Alliance
The GLBT Community Center of Colorado
The Global Justice Institute
The Global Network of People Living with HIV, North America (GNP+NA)
The Health Initiative, Inc. (Atlanta)

The Montrose Center
The Trevor Project
TILTT, Inc. (Atlanta)
Training to Serve (St. Paul)
Trans Advocacy Network
Transgender Education Network of Texas
Transgender Law Center
Transgender Legal Defense & Education Fund
Trans-Miami
UCHAPS: Urban Coalition for HIV/AIDS Prevention Services
UCSF Center of Excellence for Transgender Health
UCSF LGBT Resource Center
University of California, Davis School of Medicine
Utah Health Policy Project
Utah Pride Center
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