

Fenway Health comments on Stage 3 proposed Meaningful Use Guidelines

Department of Health and Human Services
Office of the National Coordinator for Health Information Technology
Farzad Mostashari, M.D., Sc.M., National Coordinator
HIT Policy Committee Request for Comment Regarding the Stage 3 Definition of
Meaningful Use of Electronic Health Records

Judith Bradford, PhD
Director, The Center
for Population Research in
LGBT Health
Co-Chair, The Fenway
Institute

Kenneth Mayer, MD
Medical Research Director
Co-Chair, The Fenway
Institute

Submitted online at www.regulations.gov on December 19, 2012.

Dear Dr. Mostashari,

FACULTY

Stephen Boswell, MD
Senior Research Scientist

Sean Cahill, PhD
Director of Health Policy
Research

Patricia Case, ScD, MPH
Senior Research Scientist

Harvey Makadon, MD
Director, National LGBT
Health Education Center

Matthew Mimiaga, ScD, MPH
Affiliated Investigator

Jennifer Mitty, MD, MPH
Affiliated Investigator

Conall O'Cleirigh, PhD
Affiliated Investigator

David W. Pantalone, PhD
Research Scientist

Lori Panther, MD, MPH
Research Scientist

Sari L. Reisner, MA
Associate Research Scientist

Steve Safren, PhD
Affiliated Investigator

Scout, PhD
Director, Network for LGBT
Health Equity

S. Wade Taylor, PhD
Associate Research Scientist

Aimee Van Wagenen, PhD
Associate Research Scientist

Rodney VanDerwarker, MPH
Administrative Director

We write on behalf of the Fenway Institute at Fenway Health in Boston to comment on the HIT Policy Committee Request for Comment Regarding the Stage 3 Definition of Meaningful Use of Electronic Health Records issued November 7, 2012. The Fenway Institute works to make life healthier for those who are lesbian, gay, bisexual, and transgender (LGBT), people living with HIV/AIDS, and the larger community. We do this through research and evaluation, education and training, and public health advocacy. **Fenway Health** works to enhance the wellbeing of the LGBT community and all people in our neighborhoods and beyond through access to the highest quality health care, education, research and advocacy.

We strongly support the inclusion of sexual orientation and gender identity data collection in Stage 3 Meaningful Use Guidelines. Gathering such demographic information in Electronic Health Records (EHR) is recommended by:

- The 2011 Institute of Medicine report on LGBT health;
- Healthy People 2020
- The Affordable Care Act (Section 4302); and
- The Joint Commission's 2010 report, *Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care: A Roadmap for Hospitals*.

We applaud the draft Stage 3 requirement that there be sexual orientation and gender identity functionality in EHR that is "certified" by the Office of the National Coordinator of Health Information Technology. We are, however, disappointed that the draft Stage 3 Meaningful Use Guidelines do not include sexual orientation and gender identity data collection as requirements for hospitals, physicians, and eligible providers. We strongly urge you to reconsider this omission in the interest of improving health care for LGBT people and reducing disparities.

The 2011 Institute of Medicine report on LGBT health highlighted health disparities among LGBT people, such as: the prevalence of STIs and HIV (with 64% of new cases of HIV occurring in gay or bisexual men in 2009), and the high rates of behavioral health issues and suicidality, often related to stigma, discrimination, and bullying and hate crimes. Lesbians are more likely than heterosexual and bisexual women to be

overweight and obese, increasing their risk for cardiovascular disease, lipid abnormalities, glucose intolerance, and morbidity related to inactivity.¹

The Massachusetts Behavioral Risk Factor Surveillance Survey found poorer health among bisexual respondents compared with gay, lesbian, and heterosexual respondents, as well as higher rates of mental health issues and smoking.² There are few providers well versed in the unique health care needs of transgender patients, creating a barrier to accessing quality care.

The Institute of Medicine recommends that sexual orientation and gender identity questions be asked in clinical settings and be standardized to allow for the comparison and pooling of data to analyze the unique needs of LGBT people.³ Healthy People 2020, which calls for the elimination of LGBT health disparities, also calls for gathering such data by clinicians.⁴ Gathering LGBT data in clinical settings is consistent with efforts of the U.S. Department of Health and Human Services to gather health data on LGBT populations as authorized under Section 4302 of the Affordable Care Act.⁵

A provider's knowledge of a patient's sexual orientation and gender identity is essential to providing appropriate prevention screening and care.⁶ Patients who disclose their sexual orientation identity to health care providers may feel safer discussing their health and risk behaviors as well.⁷ Gathering sexual orientation and gender identity data will increase our understanding of LGBT health disparities and how to prevent, screen and detect early health conditions that disproportionately affect LGBT people. Gathering such data in clinical settings will allow providers to better understand and treat their patients, and to compare their patients' health outcomes with national samples of LGB or LGBT people from national health surveys.⁸

Fenway Health recently evaluated the best way to ask about sexual orientation on its patient registration form. Based on this evaluation, the following question has been added:

Do you think of yourself as:

¹ Boehmer U, Bowen DJ, Bauer GR. Overweight and obesity in sexual minority women: evidence from population-based data. *Am J Public Health*. 2007; 97: 1134-1140. Cited in Mayer KH, Bradford JB, Makadon HJ, Stall R, Goldhammer H, Landers S. Sexual and gender minority health: What we know and what needs to be done. *Am J Public Health*. 2008; 98: 989-995.

² Conron, KJ, Mimiaga, MJ, Landers, SJ. A population-based study of sexual orientation identity and gender differences in adult health. *Am J Public Health*. 2010; 100(10); 1953-1960.

³ Committee on Lesbian, Gay, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities; Board on the Health of Select Populations; Institute of Medicine, *The Health of Lesbian, Gay, Bisexual, and Transgender (LGBT) People: Building a Foundation for Better Understanding*, Washington, DC: National Academies Press, 2011.

http://www.nap.edu/catalog.php?record_id=13128. Accessed July 6, 2011.

⁴ Health care providers should "appropriately inquire about and be...supportive of a patient's sexual orientation to enhance the patient-provider interaction and regular use of care."

⁵ U.S. Department of Health and Human Services. Affordable Care Act to improve data collection, reduce health disparities. News release. June 29, 2011. www.hhs.gov/news/press/2011pres/06/20110629a.html Accessed September 28, 2011.

⁶ Ibid.

⁷ Klitzman, RL, Greenberg, JD. Patterns of communication between gay and lesbian patients and their health care providers. *J Homosex*. 2002; 42(4); 65-75.

⁸ These include the National Survey of Family Growth and the National Survey of Sexual Health and Behavior, which ask about sexual orientation. Gates, G. *How many people are lesbian, gay, bisexual, and transgender?* Los Angeles: UCLA Williams Institute. 2011.

- __ *Lesbian, gay or homosexual*
- __ *Straight or heterosexual*
- __ *Bisexual*
- __ *Something else*
- __ *Don't know*

We have also conducted research on how best to ask a gender identity question on registration forms. Based on our research with transgender patients, we are now using the following question:

What is your gender?

- Female
- Male
- Genderqueer or not exclusively male or female

What was your sex at birth?

- Female
- Male

Do you identify as transgender or transsexual?

- Yes
- No
- Don't know

LGBT people have long been highly invisible to the health care system, even as they experience disparities in health outcomes and care. Few health providers are trained in LGBT health issues. A recent survey of deans of medical education at medical schools in the US and Canada found that the median time dedicated to teaching LGBT-related content in the entire medical school curriculum was five hours. One third of medical schools reported that zero hours of LGBT content were taught. Only 24% of the medical school deans considered their school's overall coverage of LGBT material as "good" or "very good" on a 5-category Likert scale.⁹

Nonetheless, many health care organizations are moving forward with gathering sexual orientation and gender identity data in clinical settings to better address the needs of their LGBT patients. We believe that health providers should routinely gather LGBT data just as they gather data on race and ethnicity. If sexual and gender minorities are to receive health care equity, this is essential.

While the inclusion of an LGBT health topic area in HP2020 is welcome, few objectives have yet been created toward the expressed goal of eliminating LGBT health disparities. Gathering LGBT data in health records is essential to our ability to track HP2020 LGBT health objectives. If OHIT does not ask and include LGBT data collection in Stage 3 Meaningful Use Guidelines, this critical step in the implementation of HP2020 cannot come to fruition.

⁹ Obedin-Maliver, J, Goldsmith, ES, Stewart, L, White, W, Tran, E, Brenman, S, Wells, M, Fetterman, DM, Garcia, G, Lunn, MR. Lesbian, gay, bisexual and transgender-related content in undergraduate medical education. *JAMA*. 2011; 306: 971-977.

Opponents of asking these questions in clinical settings will raise potential barriers, just as opponents of gathering such data on national health surveys have. Any potential barriers or concerns are surmountable and addressable. One such concern is privacy and confidentiality. Sections 1411(g), 1411(c) (2), and 1414(a) (1) of the 2010 Patient Protection and Affordable Care Act provide privacy and security protections for information used by Health Insurance Exchanges.¹⁰ A rule proposed in July 2011 would mandate “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.¹¹

Health professionals will need training to be culturally competent to gather this information from patients. Such training should occur in a broader context of training all health professionals and health center staff in the unique issues raised when caring for LGBT people to ensure that the data are gathered and used properly, and that confidentiality and privacy are respected and protected. Nevertheless, we believe that it is important to begin the process of gathering these data so we can learn more about LGBT health needs and inform training in the future. We also support a study of the most effective ways to gather sexual orientation and gender identity information in order to optimize the data collection using ways that are most acceptable to consumers.

We urge the Office of Health Information Technology to demonstrate the visionary leadership required to mandate the gathering of sexual orientation and gender identity data in clinical settings. We know how to ask these questions and how to ensure that most patients answer them honestly and without fear or stigma. We are happy to answer any questions you may have, and to work with you to improve health care data management in the United States as a key step toward reducing and eventually eliminating LGBT health disparities.

Sincerely,

Judith Bradford, Ph.D.
Co-Director
Fenway Institute

Kenneth Mayer, M.D.
Co-Director
Fenway Institute
Professor, Harvard Medical School

Stephen Boswell, M.D.
President and CEO
Fenway Health

Sean Cahill, Ph.D.
Director, Health Policy Research

¹⁰ *Patient Protection and Affordable Care Act; Establishment of Exchanges and Qualified Health Plans. A Proposed Rule by the Health and Human Services Department on 07/15/2011. Federal Register.* <http://www.federalregister.gov/articles/2011/07/15/2011-17610/patient-protection-and-affordable-care-act-establishment-of-exchanges-and-qualified-health-plans#p-252>

Accessed September 28, 2011.

¹¹ *Ibid.*

Fenway Institute

Eugenia Handler, M.S.W.
Director of Government Relations
Fenway Health

Harvey Makadon, M.D.
Director, National LGBT Health Education Center
Fenway Institute
Clinical Professor of Medicine, Harvard Medical School

Rodney Vanderwarker, M.P.H.
Administrative Director
Fenway Institute