



Department of Health and Human Services
Office of the National Coordinator for Health Information Technology
Farzad Mostashari, M.D., Sc.M., National Coordinator

RE: HIT Policy Committee Request for Comment Regarding the Stage 3 Definition of Meaningful Use of Electronic Health Records

Submitted online at www.regulations.gov on January 14, 2013.

Dear Dr. Mostashari,

We are a coalition of 145 community health centers, public health organizations, groups working on lesbian, gay, bisexual, and transgender (LGBT) health, and HIV/AIDS organizations. We write 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.

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 supported by:

- The 2011 Institute of Medicine (IOM) report on LGBT health;
- The 2012 IOM workshop summary report on collecting sexual orientation and gender identity data in EHR;
- Healthy People 2020;
- Section 4302 of the Affordable Care Act; 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 propose to retire the existing demographics objective. The collection of a range of demographic data is critical to the success of the Meaningful Use effort, and it is unfeasible to imagine that this vital objective can be considered complete in Stage 2.

Moreover, we are concerned that the draft Stage 3 guidelines do not include sexual orientation and gender identity data collection as requirements for eligible hospitals and professionals. We strongly urge you to reconsider this omission in the interest of improving health care for LGBT people and reducing disparities. Specifically, we recommend that the demographics objective be retained as a core objective in Stage 3, with a slightly higher threshold (e.g., 85 percent) to promote progress past the Stage 2 level, and that it incorporate sexual orientation and gender identity data collection. Doing so acknowledges that demographic information, including sexual orientation and gender identity, is an important part of high-quality, patient-centered care. It will also encourage eligible professionals and hospitals to utilize the LGBT data collection functionality in their EHR systems that the draft Stage 3 guidelines require.

Training and data collection must go hand-in-hand.

As many speakers at the October 2012 IOM workshop on LGBT data collection in EHR systems noted, health professionals and administrative staff need training in LGBT cultural competence to appropriately gather this information from patients. Such training should occur in a broader context of training health professionals and administrative staff in fully incorporating the requirements of Meaningful Use into their daily work. Beginning the process of gathering these data as part of the implementation of Meaningful Use is crucial to the ability of researchers and clinicians to learn more about LGBT health needs and inform training in the future. As part of this effort, 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.

LGBT data is important in clinical settings.

The importance of sexual orientation and gender identity in clinical settings is significant. The 2011 Institute of Medicine report on LGBT health highlighted substantial 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 Moreover, there are few providers well versed in the health care needs of transgender patients, creating a barrier to accessing quality care.

Reflecting these disparities, 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

The recent IOM workshop also noted the benefits of collecting sexual orientation and gender identity data in EHR systems. 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

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.

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

⁶ Ibid.

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. Finally, 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

Collecting these data also helps address the fact that 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

Collecting sexual orientation and gender identity data in clinical settings is feasible and appropriate.

As documented by the IOM report, 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, ethnicity, and other aspects of identity associated with health and health care access disparities.

For example, Fenway Health in Boston 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:

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

Fenway Health also conducted research on how best to ask a gender identity question on registration forms. Based on research with transgender patients, Fenway Health is now using the following series of questions, including a birth sex question:

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.

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.

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

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

ONC's leadership through the Meaningful Use process is a critical component of closing the LGBT health disparities gap.

We urge the Office of the National Coordinator for Health Information Technology to demonstrate the visionary leadership required to institutionalize the routine 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 we look forward to working with you to improve health care data management in the United States as a key step toward reducing and eventually eliminating LGBT health disparities. (Contact: Sean Cahill at the Fenway Institute, scahill@fenwayhealth.org, or Kellan Baker at the Center for American Progress, kbaker@americanprogress.org.)

Sincerely,

Fenway Health
Center for American Progress

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>

¹¹ Ibid.

ActionAIDS
Affirmations
AIDS Action Baltimore
AIDS Community Research Initiative of America
AIDS Foundation of Chicago
AIDS Ministries AIDS Assist
AIDS Resource Center of Wisconsin
AIDS Resource Center Ohio
AIDS United
American Psychological Association
amfAR, the Foundation for AIDS Research
Asian & Pacific Islander American Health Forum
Association of Asian Pacific Community Health Organizations
Basic Rights Oregon
BiNet USA
Bisexual Resource Center
Boston Bisexual Women's Network
Boston Pride Human Rights and Education Committee
BRMG Diversity Consultants
Brooklyn Community Pride Center
California Lesbian, Gay, Bisexual, and Transgender Health and Human Services Network
Callen-Lorde Community Health Center
Center of Excellence for Transgender Health, UCSF
Center for HIV Law and Policy
Center on Halsted
CenterLink: The Community of LGBT Centers
Community Health Awareness Council
Coalition of Lavender-Americans on Smoking and Health (CLASH)
Coalition for LGBT Health
Colorado AIDS Project
Colorado Consumer Health Initiative
Colorado Organization for Latina Opportunity and Reproductive Rights (COLOR)
Community Health Applied Research Network (CHARN)
CHARN Alliance of Chicago Community Health Services Node
CHARN Association of Asian Pacific Community Health Organizations Node
CHARN Fenway Health Node
CHARN OCHIN, Inc. (Oregon) Node
CHARN Coordinating Center
Contra Costa Health Services
David Ostrow & Associates
Empire State Pride Agenda
Equality California Institute
Equality Federation
Equality Florida Institute, Inc.
Erie Family Health Center
Ethos
Fair Wisconsin
Family Equality Council
FORGE, Inc. (For Ourselves, Reworking Gender Expression)

Gay Men's Health Crisis
Georgia Equality
Gerontology Program - Bowling Green State University
GLBT Community Center of Colorado
Gay and Lesbian Medical Association: Health Professionals Advancing LGBT Equality
Greater Palm Springs Pride
HealthHIV
Healthy Communities of the Capital Area: Maine
HIV Medicine Association
HIV Prevention Justice Alliance
Housing Works
Hudson Pride Connections Center
Illinois Campaign for Better Health Care
Indiana Youth Group
International Rectal Microbicides Advocates
Kaleidoscope Youth Center
Kansas Health Consumer Coalition
Kansas Health Consumer Coalition
Los Angeles Gay & Lesbian Center
Larkin Street Youth Services
Lehmann Consulting, Inc.
Lesbian Health & Research Center, University of California - San Francisco
LGBT Aging Project
LGBT Center of Raleigh
LGBT Center of SE Wisconsin
Lyon-Martin Health Services
Massachusetts Commission on LGBT Youth
Maryland Citizens' Health Initiative Education Fund
Maryland Women's Coalition for Health Care Reform
Mass Equality
Mass Home Care
Mendocino County AIDS/Viral Hepatitis Network
Mental Health America of San Diego
Michigan Consumers for Healthcare
Moveable Feast
Multicultural AIDS Coalition
Multnomah County Health Department, Portland, OR
National Asian Pacific American Women's Forum
National Center for Lesbian Rights
National Center for Transgender Equality
National Coalition for LGBT Health
National Coalition of Anti-Violence Programs
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 Women's Law Center
National Youth Pride Services
New Jersey Citizen Action

New Mexico GLBTQ Centers
New York City Gay and Lesbian Anti-Violence Project
New York City LGBT Community Center
North Shore Alliance of GLBT Youth
One Colorado
Our Family Coalition
OutFront Minnesota
Population Council
Progressive Leadership Alliance of Nevada
Project Inform
Q Center
Queer Humboldt
Racial and Ethnic Health Disparities Coalition
Rainbow Health Initiative
Raising Women's Voices
REAL: Hawaii Youth Movement Exposing the Tobacco Industry
Resource Center Dallas
Richmond Gay Community Foundation
RU12? Community Center
Ruth Ellis Center
Sacramento Gay and Lesbian Center
SAGE Metro St Louis
Services and Advocacy for GLBT Elders (SAGE)
Sexuality Information and Education Council of the United States
Society for Public Health Education
South Bay Gay & Lesbian Community Organization, Inc.
Spectrum LGBT Center
The AIDS Institute
The DC Center for the Lesbian, Gay, Bisexual, and Transgender Community
The Family Tree Community Center, Inc.
The LGBT Center of St. Louis
The Network for LGBT Health Equity
The Trevor Project
Time Out Youth
Transgender Law Center
Universal Health Care Action Network of Ohio
University of Medicine and Dentistry of New Jersey School of Nursing
Unity Michigan Coalition
Utah Pride Center
VillageCare
Western Montana LGBT Community Center
Whitman-Walker Health
William Way LGBT Community Center
Williams Institute, UCLA School of Law
Wisconsin Alliance for Women's Health
WV FREE

Cc: Dr. Howard Koh, Assistant Secretary for Health, U.S. Department of Health and Human Services, Co-chair, HHS LGBT Coordinating Committee

Caya Lewis, Director of Outreach and Public Health Policy, Office of Health Reform, DHHS

Dr. Grant Colfax, Director, White House Office of National AIDS Policy

Gautam Raghavan, Associate Director, White House Office of Public Engagement

Dr. Jeanne Lambrew, Deputy Assistant to the President for Health Policy

Dr. Donald Moulds, Acting Assistant Secretary for Planning and Evaluation, DHHS

Dr. Yael Harris, Director, Office of Health IT and Quality, HRSA

Robert Tagalicod, Director, Office of eHealth Standards and Services at CMS

Sue McAndrew, Deputy Director of HIT Privacy, Office for Civil Rights, DHHS

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Amanda Curylo, Special Assistant to the National Coordinator for Health Information Technology