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Andrew Slavitt
Acting Administrator
Centers for Medicare & Medicaid Services
Department of Health and Human Services
Attention: CMS-3310-P
P.O. Box 8013
Baltimore, MD 21244-8013

Public Comment on Stage 3 Meaningful Use proposed rule CMS-3310-P, 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 Mr. Slavitt:

We write to comment on the Stage 3 Meaningful Use proposed rule, released by CMS on 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 deeply disappointed that the collection and use of sexual orientation and gender identity (SO/GI) are not explicitly included in the Stage 3 proposed rule.** This is a major missed opportunity to take an important step toward better understanding, addressing, and reducing LGBT health disparities. It is inconsistent with all of the steps the federal government has taken over the past six years to increase SO/GI data collection in health care settings and on surveys.

Helping to address LGBT disparities via the consistent collection of SO/GI data has become a significant priority for HHS. For instance, over the last several years the department has:

- Drawn on its authority under Section 4302 of the Affordable Care Act to develop a strategy for expanding the collection of SO/GI data through its flagship health survey, the National Health Interview Survey.
- Developed a SO/GI data collection module for the largest federally supported health survey, the Behavioral Risk Factor Surveillance System (BRFSS). In 2014 alone, 19 states plus Guam added this module to their BRFSS questionnaires, in addition to approximately a dozen other states and territories that already asked about sexual orientation and/or gender identity using questions that differ from this module.

- Increasingly added sexual orientation and/or gender identity demographic questions to surveys and programmatic data collection instruments at the Substance Abuse and Mental Health Services Administration, the Health Resources and Services Administration, and other divisions across the department.

The failure of CMS to include SO/GI in Meaningful Use Stage 3 also ignores the recommendations of the Institute of Medicine, the Joint Commission, and leading LGBT health researchers across the U.S. in support of including SO/GI data collection as part of Meaningful Use guidelines.

Despite advances in legal protections for LGBT people that have occurred over the last several decades, many barriers to good health and high-quality health care remain. As recommended by both the Institute of Medicine¹ and the Joint Commission,² collecting data on sexual orientation and gender identity in health care settings is essential to providing high-quality, patient-centered care to LGBT individuals. Collecting SO/GI data is also an important part of learning more about and addressing LGBT health disparities. In recent years, LGBT health experts and health policymakers have reached consensus regarding the relative dearth of data on LGBT health and the importance of increasing SO/GI data collection in clinical settings and in electronic health records (EHRs) in order to better understand LGBT health disparities and inform interventions to reduce and eliminate them.³

A growing body of research has documented LGBT health disparities in health and disease outcomes,^{4,5} risk behaviors and factors,^{6,7} rates of insurance coverage,^{8,9} access to preventive care,^{10,11} and access to culturally competent care.¹² Because most clinical records systems do not support the collection of structured SO/GI data, however, LGBT people are often invisible in care settings. This invisibility masks disparities and impedes the provision of important health care services for LGBT individuals, such as appropriate preventive screenings, assessments of risk for sexually transmitted infections such as HIV, and effective interventions for behavioral health concerns that may be related to experiences of anti-LGBT stigma and discrimination. Like all patients, LGBT people have many concerns related to their relationships, desire to have families, and issues of aging that occur in different stages of the life cycle. An opportunity to share information about their sexual orientation and gender identity in a welcoming environment will facilitate important conversations with clinicians who are in a position to be extremely helpful.

Knowledge of a patient's sexual orientation or gender identity can be an important part of treatment. For example, transgender women who were assigned 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. If providers do not know that their patient is gay or transgender, they do not know to do these screenings.

The stated goals of the Meaningful Use program are to:

- Reduce health disparities
- Engage patients and families
- Improve care coordination
- Improve population health and public health
- Ensure adequate privacy and security protections for personal health information

All of these goals are important to LGBT people. Without SO/GI data collection by providers, how can we reduce LGBT health disparities? How can we meaningfully engage LGBT patients and their families, and improve care coordination? How can we improve LGBT population health and public health? In order to substantively advance the goals of the Meaningful Use program, the collection of SO/GI should at a minimum be recommended and incentivized, if not required.

While the inclusion of SO/GI was considered during the Stage 2 rule making process, SO/GI were ultimately not included because of an alleged lack of consensus on how to measure these concepts and because some commenters questioned the clinical significance of providers asking their patients about SO/GI. Since then researchers with the Community Health Applied Research Network demonstrated that SO/GI questions are acceptable to a diverse patient population in health centers that are diverse in terms of geography, gender, region, race/ethnicity, sexual orientation, and age.¹³ And more than 150 organizations representing health care researchers, providers, and professional organizations have expressed support for asking SO/GI questions in clinical settings and tracking this information in EHRs.¹⁴ In the specific context of transgender health, the World Professional Association for Transgender Health has published recommendations for collecting and using gender identity data in clinical settings.¹⁵ **There is a strong consensus regarding how to ask SO/GI questions in clinical settings and the importance of tracking these data in EHRs.**

We recently commented on the draft Interoperability Standards Advisory published by the Office of the National Coordinator of Health Information Technology on January 28, 2015. This advisory identified SNOMED CT codes for sexual orientation and gender identity. In our May 1, 2015 comment, we commended ONC for including SO/GI in the draft Interoperability Standards Advisory. We encouraged ONC to work with the National Library of Medicine to improve the existing SNOMED CT codes and to use this opportunity to institute adoption of a single standard of SO/GI questions and answers (including the three fields of sexual orientation, gender identity, and assigned sex at birth) that were developed with LGBT community input and validated in peer-reviewed research.¹⁶

We know that ONC has proposed to require that a health IT module enable a user to record, change, and access SO/GI data in its proposed Certified Health IT rule. In our comment to ONC we commend them for this, and urge them to include SO/GI in the Demographics criterion (as included in the Base EHR definition) and in the Common Clinical Data Set. Such inclusion could increase the incorporation of SO/GI fields into EHR software. However, this would do nothing to encourage the collection of SO/GI data by providers, and its use to improve patient care, for example in decision support for preventive screenings. It would do nothing to reduce LGBT disparities. **Only the explicit inclusion of SO/GI in the Stage 3 Meaningful Use guidelines can accomplish this objective.**

We strongly urge CMS to reconsider the proposed rule, and explicitly require the collection and use of SO/GI data in Stage 3 Meaningful Use. Promoting SO/GI data collection in EHRs is one of the most important things the federal government could do right now to address LGBT health disparities. CMS's failure to take this step would represent a major missed opportunity to encourage providers to discuss SO/GI with their patients, and a major missed opportunity to address LGBT health disparities and improve health care for LGBT people. Explicit inclusion of SO/GI in Stage 3 Meaningful Use is essential to improve data collection in EHRs and increase health information exchange to improve health outcomes for LGBT patients.

Thank you for considering this comment. We look forward to continuing to work with CMS and ONC to improve SO/GI data collection in EHRs to better understand and reduce LGBT health disparities. Should you have any questions or wish to discuss these issues, 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 Committee on Lesbian, Gay, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities; Board on the Health of Select Populations; Institute of Medicine. 2011. *The Health of Lesbian, Gay, Bisexual, and Transgender (LGBT) People: Building a Foundation for Better Understanding*. Washington, DC: National Academies Press.
- ² 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
- ³ 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
- ⁴ Committee on Lesbian, Gay, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities; Board on the Health of Select Populations; Institute of Medicine. 2011. *The Health of Lesbian, Gay, Bisexual, and Transgender (LGBT) People: Building a Foundation for Better Understanding*. Washington, DC: National Academies Press.
- ⁵ Boehmer U, Bowen DJ, Bauer GR. 2007. "Overweight and Obesity in Sexual Minority Women: Evidence from Population-Based Data." *American Journal of Public Health* 97:1134–40. doi:10.2105/AJPH.2006.088419.
- ⁶ Committee on Lesbian, Gay, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities; Board on the Health of Select Populations; Institute of Medicine. 2011. *The Health of Lesbian, Gay, Bisexual, and Transgender (LGBT) People*.
- ⁷ Lee J, Griffin G, Melvin C. 2009. "Tobacco Use among Sexual Minorities in the U.S.A., 1987 to May 2007: A Systematic Review." *Tobacco Control* 18(4):275–82. doi:10.1136/tc.2008.028241.
- ⁸ Ponce N, Cochran S, Pizer J, et al. 2010. "The Effects of Unequal Access to Health Insurance for Same-Sex Couples in California." *Health Affairs* 29:1539–48. doi:10.1377/hlthaff.2009.0583.
- ⁹ Ranji U, Beamesderfer A, Kates J, et al. 2014. *Health and Access to Care and Coverage for Lesbian, Gay, Bisexual, and Transgender Individuals in the U.S.* Menlo Park, CA: Henry J. Kaiser Family Foundation. <http://kff.org/report-section/health-and-access-to-care-and-coverage-for-lgbt-individuals-in-the-u-s-health-challenges/>.
- ¹⁰ Valanis, BG, Bowen DJ, Bassford T, et al. 2000. "Sexual Orientation and Health: Comparisons in the Women's Health Initiative Sample." *Archives of Family Medicine* 9:843–53. PMID: 11031391.
- ¹¹ Grant JM, Mottet LA, Tanis J, et al. 2011. *Injustice at Every Turn: A Report of the National Transgender Discrimination Survey*. Washington, DC: National Center for Transgender Equality and National Gay and Lesbian Task Force.
- ¹² Lambda Legal. 2010. *When Health Care Isn't Caring: Lambda Legal's Survey of Discrimination against LGBT People and People with HIV*. New York: Lambda Legal. Available at: http://www.lambdalegal.org/sites/default/files/publications/downloads/whcic-report_when-health-care-isnt-caring.pdf.
- ¹³ Institute of Medicine. *Sexual orientation and gender identity data collection in electronic health records. A workshop*. October 12, 2012. Available at www.iom.edu/Activities/SelectPops/LGBTDData.aspx
- ¹⁴ 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. Submitted by the Fenway Institute, the Center for American Progress, and 151 other organizations. April 28, 2014. Available at <http://thefenwayinstitute.org/wp-content/uploads/TFI-CAP-150+-Orgs-Public-Comment-re-MU-Stage-2-04.28.14.pdf>
- ¹⁵ Deutsch MB, Green J, Keatley JA, et al. 2013. "Electronic medical records and the transgender patient: recommendations from the World Professional Association for Transgender Health EMR Working Group." *J Am Med Inform Assoc*. doi:10.1136/amiajnl-2012-001472.
- ¹⁶ 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.