FOR IMMEDIATE RELEASE
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The Fenway Institute, Center for American Progress applaud new U.S. Department of Health and Human Services rule including sexual orientation and gender identity in the Meaningful Use of Electronic Health Records program

The Fenway Institute and the Center for American Progress applaud the U.S. Department of Health and Human Services for taking the landmark step of addressing disparities affecting lesbian, gay, bisexual, and transgender (LGBT) people in health care by including sexual orientation and gender identity (SO/GI) data in requirements for Electronic Health Records (EHRs) certified under the Meaningful Use program.

The new final rules, from the Centers for Medicare and Medicaid Services (CMS) and the Office of the National Coordinator of Health Information Technology (ONC), require all EHR systems certified under Stage 3 of Meaningful Use to allow users to record, change, and access structured data on sexual orientation and gender identity. This requirement is part of the 2015 Edition “demographics” certification criterion and adds SO/GI data to the 2015 Edition Base EHR definition, which is a part of the definition of Certified EHR Technology (CEHRT).

The rules note that this requirement will “help those within the patient’s care team to have more information on the patient that can aid in identifying interventions and treatments most helpful to the particular patient,” citing the example of a transgender man—an individual who was assigned female at birth and identifies as male—who should be offered a cervical exam if he still retains a cervix.

The ONC rule notes that certification does not require providers to collect SO/GI information. Rather, the requirement applies to vendors who are building certified EHR systems and health institutions and practices that are using these systems as part of their participation in the Meaningful Use program.

The ONC rule also adopts recommendations relating to replacing outdated and offensive terminology in the code sets relating to SO/GI and endorses tested sexual orientation and gender identity question designs as “best practice” questions for health care providers and institutions to consider adopting for their electronic SO/GI data collection efforts.

“Including sexual orientation and gender identity in the Meaningful Use incentive program is one of the most important things our government has done to promote better understanding of LGBT health disparities and interventions to reduce them,” said Sean Cahill, Director of Health Policy Research at the Fenway Institute.
“At the 2012 Institute of Medicine workshop on this topic I testified to the clinical importance of providers knowing their patients’ sexual orientation and gender identity, including the need to offer transgender individuals appropriate preventive screenings in a sensitive manner,” said Harvey Makadon, M.D., Director of Education and Training at the Fenway Institute and a member of the Institute of Medicine committee that oversaw the 2011 report on LGBT health.

“Authoritative sources such as the Institute of Medicine, the Joint Commission, and Healthy People 2020 have all emphasized the importance of collecting more and better data on the health needs and experiences of LGBT people,” said Kellan Baker, Senior Fellow with the LGBT Research and Communications Project at the Center for American Progress. “Including SO/GI in the demographics criterion for EHR Meaningful Use is a crucial step forward to improving care for LGBT communities.”

The new requirements are currently slated to take effect in 2018, which offers a critical window of time for work to provide technical assistance to providers, health systems, and vendors relating to the collection of these data. With generous support from the Robert Wood Johnson Foundation, Fenway and CAP have been providing technical assistance to health system stakeholders from across the U.S. who are in the process of adding SO/GI questions into their EHR systems. As part of this project—titled “Do Ask, Do Tell”—Fenway and CAP have developed an online toolkit for collection SO/GI data in EHRs that can be accessed at www.doaskdotell.org.

The Fenway Institute, CAP, the Mayo Clinic, and more than 100 other health care, research, professional, and patient advocacy organizations also submitted comments to CMS and ONC encouraging the step of requiring certified EHR systems to have the capacity to collect SO/GI data.

A number of key steps remain to make meaningful SO/GI data collection in clinical settings a reality, including training clinical staff in how to collect and use SO/GI data, talking with LGBT community members about the importance of these data and applicable privacy and confidentiality protections, and ensuring that robust nondiscrimination protections are in place throughout the health care system—including the proposed federal regulations implementing Section 1557, the civil rights provision of the Affordable Care Act, which are open for comment until November 9. Fenway and CAP convened 20 experts from around the country in June 2015 to plan the next phase of work. This group includes leaders from the American Medical Association, the National Association of Community Health Centers, Kaiser Permanente, the Veterans Health Administration, Partners Healthcare, the Human Rights Campaign, and many other institutions.

For more on this topic, please see www.doaskdotell.org.

Since 1971, Fenway Health has been working to make life healthier for the people in our neighborhood, the LGBT community, people living with HIV/AIDS and the broader population. The Fenway Institute at Fenway Health is an interdisciplinary center for research, training, education and policy development
focusing on national and international health issues. Fenway’s Sidney Borum Jr. Health Center cares for youth and young adults ages 12 to 29 who may not feel comfortable going anywhere else, including those who are LGBT or just figuring things out; homeless; struggling with substance use; or living with HIV/AIDS. In 2013, AIDS Action Committee of Massachusetts joined the Fenway Health family, allowing both organizations to improve delivery of care and services across the state and beyond.

The Center for American Progress is an independent nonpartisan educational institute dedicated to improving the lives of Americans through progressive ideas and action. Alongside numerous issue areas, CAP’s priorities include health, LGBT issues, and the importance of data-driven policy solutions. Founded in 2003 to provide long-term leadership and support to the progressive movement, CAP is based in Washington, D.C.