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Submitted online at <http://www.healthit.gov/policy-researchers-implementers/interoperability-roadmap-public-comments>

Office of the National Coordinator for Health Information Technology
Department of Health and Human Services
Attention: Interoperability Roadmap Public Comments
Hubert H. Humphrey Building, Suite 729D
200 Independence Ave, S.W.
Washington, D.C. 20201

Public Comment on draft *Shared Nationwide Interoperability Roadmap* released January 30, 2015

Submitted by the Fenway Institute, the Center for American Progress, and nine other health research, health professional, and patient advocacy organizations

Dear Dr. DeSalvo:

We write to comment¹ on *Connecting Health and Care for the Nation: A Shared Nationwide Interoperability Roadmap Draft Version 1.0*, released by ONC January 30, 2015.

As health care providers, researchers, educators, and advocates, we share your goal of creating “a nationwide learning health system—an environment that links the care delivery system with communities and societal supports in ‘closed loops’ of electronic health information flow, at many different levels, to enable continuous learning and improved health.” (8) We also agree that “standardized data elements, such as demographics,...will enable better matching and linking of electronic health information across all systems and platforms.” (10) Finally, we support the objectives included in ONC’s definition of interoperability:

...the ability of an system to exchange electronic health information with and use electronic health information from other systems without special effort on the part of the user...[T]his means *all individuals, their families and their health care providers have appropriate access to electronic health information that facilitates informed decision-making, supports coordinated health management, allows individuals and caregivers to be active partners and participants in their health and care and improves the overall health of the nation’s population.* (18, emphasis added)

We believe that in order for all of this to be true for lesbian, gay, bisexual and transgender (LGBT) Americans, **it is essential that sexual orientation and gender identity (SO/GI) be added to the “Common Clinical Data Set for purposes of treatment” called for in the Nationwide Interoperability Roadmap** (34). 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. We understand that draft Stage 3 meaningful use guidelines are not requiring collection of these data. However, we are suggesting that consistent with the Institute of Medicine's recommendation in its groundbreaking 2011 report on LGBT health, the collection of sexual orientation and gender identity data is essential "to improve health and health care quality," the stated goal of using a Common Clinical Data Set (34).

The questions developed by the CHARN network of community health centers and published in *PLOS One* in September 2014 should be considered as potential standards for SO/GI data collection that could be useful to better document and reduce LGBT health disparities.²

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 Medicine³ and The Joint Commission,⁴ 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.⁵

A growing body of research has documented LGBT health disparities in health and disease outcomes,^{6,7} risk behaviors and factors,^{8,9} rates of insurance coverage,^{10,11} access to preventive care,^{12,13} and access to culturally competent care.¹⁴

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.

Two of the four near-term priorities articulated by ONC in the *Roadmap* are:

- (2) improve technical standards and implementation guidance for sharing and using a common clinical data set; (3) enhance incentives for sharing electronic health information according to common technical standards, starting with a common clinical data set; (11)

We urge ONC to take this opportunity to add sexual orientation and gender identity to the list of demographic variables and clinical indicators listed in the Common Clinical Data Set on page 80 of the draft *Shared Nationwide Interoperability Roadmap*.

SO/GI questions proven effective in health care settings

In an effort to determine best practices for collecting SO/GI information, researchers affiliated with the Community Health Applied Research Network (CHARN)—a network of community health centers funded in 2009 to enhance applied health research—developed SO/GI questions and tested them at four health centers across the U.S. among both LGBT and heterosexual patients. The sample of 301 patients was predominantly heterosexual, and mostly Black and Latino. One third were patients at Beaufort Jasper Hampton Health Center in rural South Carolina. The questions were overwhelmingly accepted by the patients. The majority of participants—including most LGBT patients—felt the answer choices accurately reflected their identities, and most respondents felt that this information was “important for my medical provider to know about me.”¹⁵ Based on this research, we recommend the following questions:

1. Do you think of yourself as:
 - a. Straight or heterosexual
 - b. Lesbian, gay, or homosexual
 - c. Bisexual
 - d. Something else, please describe _____
 - e. Don't know

2. What is your current gender identity? (Check all that apply.)
 - a. Male
 - b. Female
 - c. Transgender male/Trans man/Female-to-male (FTM)
 - d. Transgender female/Trans woman/Male-to-female (MTF)
 - e. Genderqueer, neither exclusively male nor female
 - f. Additional gender category/(or other), please specify _____
 - g. Decline to answer, please explain why _____

3. What sex were you assigned at birth on your original birth certificate? (Check one.)
 - a. Male
 - b. Female
 - c. Decline to answer, please explain why _____¹⁶

Responding to SO/GI questions in a health care setting should always be voluntary. Providers and LGBT community members should be educated about the importance and purpose of gathering SO/GI information. It is important that clinical staff be trained in how to provide culturally competent and affirming care to LGBT patients, and how to ask about sexual orientation and gender identity as part of that process. Clinical or senior center staff should be trained in how to ask these questions in a way that is sensitive and affirming, and how to protect patient privacy and confidentiality.¹⁷ The National LGBT Health Education Center (www.lgbthealtheducation.org) offers online trainings and technical assistance to help health centers and hospitals provide culturally competent, affirming and nondiscriminatory care.

The Fenway Institute, the Center for American Progress, and the nine other health research, health professional, and patient advocacy organizations encourage you to add sexual orientation and gender identity to the Common Clinical Data Set in the draft *Shared National Interoperability Roadmap*. Please consider the questions developed by the CHARN network of community health centers and published in *PLOS One* in September 2014 as potential standards for SO/GI data collection that could be useful to better document and reduce LGBT health disparities.

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 improve data collection in EHRs and increase health information exchange to improve health outcomes. Should you have any questions, please contact Sean Cahill at scahill@fenwayhealth.org, or at 617-927-6016.

Sincerely Yours,

Fenway Institute, Fenway Health

Center for American Progress

AIDS United

Center for HIV/AIDS Research, Education, and Policy
Myrlie Evers-Williams Institute for Elimination of Health Disparities
University of Mississippi Medical Center
Jackson, MS

GLMA: Health Professionals Advancing LGBT Equality (formerly Gay and Lesbian Medical Association)

Human Rights Campaign

HIV Medicine Association

Los Angeles LGBT Center

National Association of Community Health Centers

National Partnership for Women and Families

Open Arms Healthcare Center
Jackson, MS

¹ Our comments respond to the following questions posed by ONC on pages 6-7 of the draft roadmap:

1. **General**

- Are the actions proposed in the draft interoperability Roadmap the right actions to improve interoperability nationwide in the near term while working toward a learning health system in the long term?
- What, if any, gaps need to be addressed?

6. Core Technical Standards and Functions

- Which data elements in the proposed common clinical data set list need to be further standardized? And in what way?

8. Measurement

- Does the measurement and evaluation framework cover key areas? What concepts are missing?
- Which concepts from the framework are the most important to measure? What types of measures should be included in a “core” measure set?
- Should measurement focus on certain use cases, priority populations or at certain levels of the ecosystem (e.g., encounter, patient, provider, organization)?

² Cahill, S., R. Singal, C. Grasso et al. 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.

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. 2011. *The Health of Lesbian, Gay, Bisexual, and Transgender (LGBT) People: Building a Foundation for Better Understanding*. Washington, DC: National Academies Press.

⁴ 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

⁵ 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

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: Building a Foundation for Better Understanding*. Washington, DC: National Academies Press.

⁷ Boehmer, U., D.J. Bowen, and G.R. Bauer. 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.

⁸ 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*.

⁹ Lee, J., G. Griffin, and C. Melvin. 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.

¹⁰ Ponce N., S. Cochran, J. Pizer 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.

¹¹ Ranji U., A. Beamesderfer, J. Kates 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/>.

¹² Valanis, B.G., D.J. Bowen, T. Bassford et al. 2000. “Sexual Orientation and Health: Comparisons in the Women’s Health Initiative Sample.” *Archives of Family Medicine* 9:843–53. PMID: 11031391.

¹³ Grant, J.M., L.A. Mottet, J. Tanis 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.

¹⁴ 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. http://www.lambdalegal.org/sites/default/files/publications/downloads/whcic-report_when-health-care-isnt-caring.pdf.

¹⁵ Cahill, S., R. Singal, C. Grasso et al. 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.

¹⁶ Ibid.

¹⁷ Cahill, S., and H.J. Makadon. 2014. “Sexual Orientation and Gender Identity Data Collection in Clinical Settings and in Electronic Health Records: A Key to Ending LGBT Health Disparities.” *LGBT Health* 1(1):1–8. doi:10.1089/lgbt.2013.0001.