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

Jennifer Potter, MD
LGBT Population Health Program Director & Co-Chair, The Fenway Institute

FACULTY

Kevin L. Ard, MD
Adjunct Faculty

Abigail Batchelder, PhD, MPH
Affiliated Investigator

Katie B. Biello, PhD
Research Scientist

Aaron J. Blashill, PhD
Affiliated Investigator

Stephen Boswell, MD
Senior Research Scientist

Wendy Bostwick, PhD, MPH
Adjunct Faculty

Sean Cahill, PhD
Director of Health Policy Research

Kerith J. Conron, ScD, MPH
Research Scientist

Brian Dodge, PhD
Adjunct Faculty

Holly Fontenot, PhD, RN, WHNP-BC
Adjunct Faculty

Alex Keuroghlian, MD, MPH
Director, Education & Training Programs

Douglas S. Krakower, MD
Adjunct Faculty

Lisa Krinsky, LICSW
Director of the LGBT Aging Project

Matthew Mimiaga, ScD, MPH
Senior Research Scientist

Conall O'Cleirigh, PhD
Affiliated Investigator

Bisola Ojikutu, MD, PhD
Adjunct Faculty

David W. Pantalone, PhD
Behavioral Scientist

Jennifer Putney, MSW, PhD
Adjunct Faculty

Sari L. Reisner, ScD
Research Scientist

Steve Safren, PhD
Affiliated Investigator

S. Wade Taylor, PhD
Associate Research Scientist

Marcy Gelman, RN, MSN, MPH
Director of Clinical Research

Bonnie McFarlane, MPP *Director of Administration*

February 16, 2018

Office of the National Coordinator for Health Information Technology
Submitted via email to exchangeframework@hhs.gov

RE: Comment regarding the Draft U.S. Core Data for Interoperability (USCDI) and Proposed Expansion Process

Dear colleagues,

We are writing to provide comment regarding the Draft Trusted Exchange Framework (TEF) and U.S. Core Data for Interoperability (USCDI) and Proposed Expansion Process, which together make up the Trusted Exchange Framework and Common Agreement (TEFCA).

We urge ONC to include sexual orientation and gender identity (SOGI) standards in the list of required data classes for USCDI Version 1 (USCDIv1). SOGI are required elements in the 2015 Edition Base Electronic Health Record (EHR) Definition and have been listed as mature standards in the *Interoperability Standards Advisory* (ISA) since 2017.

Inclusion of existing SOGI standards from the 2015 Edition Base EHR Definition certification criteria and ISA in USCDIv1 will strengthen the architecture of the TEF and will advance the data interoperability goals of the 21st Century Cures Act. The inclusion of existing, mature SOGI standards reflects scientific consensus and evidence-based best practices endorsed by the Department of Health and Human Services (HHS) and other key federal and non-federal stakeholders such as The Joint Commission and the U.S. Institute of Medicine.

Inclusion of SOGI standards will strengthen the TEFCA architecture in several critical problem areas. SOGI data are easily captured, simply structured, and highly interoperable demographic characteristics. Including SOGI data will greatly assist in both patient-matching and identity-proofing processes that are critical to achieving TEFCA's interoperability goals and the interoperability mandate of the 21st Century Cures Act. High quality patient-matching and identity-proofing processes for data exchanged over a Health Information Network (HIN) or other exchange infrastructure are critical to TEFCA's success.

SOGI are potentially life-saving data. In an emergency situation, SOGI data exchanged over a HIN can help ensure identity-proofing with a high degree of confidence, therein allowing emergency providers who receive data from a query to act quickly and confidently. In a non-emergency situation, SOGI data are critical to ensuring the delivery of patient-centered care, especially to

sexual and gender minorities, who are an NIH-recognized health disparities group.[1]

SOGI are fully interoperable, simply structured data associated with mature standards. SOGI have been listed as mature since the 2017 ISA, and have been a part of the ISA since it was first released in 2015. Further, SOGI data pose no special privacy risks compared to other already collected demographic data. SOGI data are less sensitive and less complex data to exchange than other categories included in USCDIv1, such as immunizations, medications, medication allergies, or health concerns.

Federally Qualified Health Centers (FQHC) are already required to collect SOGI data, and to report these data annually to the Health Resources and Services Administration Bureau of Primary Health Care (HRSA/BPHC). FQHCs make up a substantial portion of participants in HINs and associated infrastructures. This means that there is already a great deal of patient-level SOGI data available for immediate use upon TEFCA's release.

Collecting SOGI data is also good for improving health equity. Lesbian, gay, bisexual, and transgender (LGBT) people are disproportionately burdened by health disparities, and including SOGI in USCDIv1/TEFCA will contribute to the elimination of these disparities. Gay and bisexual men and transgender women, and in particular gay and bisexual men and transgender women of color, are disproportionately burdened by HIV infection.[2,3] Lesbian and bisexual women are less likely to receive preventive cancer screenings compared to heterosexual women,[4] and may be at elevated risk of breast and ovarian cancer due to higher rates of nulliparity.[5,6] According to the 2015 U.S. Transgender Survey, 40% of transgender respondents reported ever attempting suicide.[7]

In order to address these disparities, it is essential that health care facilities be able to exchange SOGI in order to ensure continuity of care across the entire continuum of care. There is a consensus among researchers, providers, and health care organizations that the collection, use, and exchange of SOGI data in clinical settings is a key strategy for reducing the health disparities experienced by sexual and gender minority populations. In 2011, the Institute of Medicine[8] and the Joint Commission[9] recommended routine SOGI data collection in electronic health records (EHRs) to enhance understanding of health disparities experienced by LGBT people and to help determine strategies to reduce these disparities. The Centers for Medicaid & Medicare Services (CMS) 2015 *Equity Plan for Medicare Beneficiaries* encourages SOGI data collection.[10]

In health IT, this overwhelming consensus about the clinical importance of SOGI data led to the addition of SOGI to the 2015 Edition Base EHR Definition and the ISA. It is only logical that SOGI be included in USCDIv1. SOGI's inclusion in USCDIv1 will not only strengthen the TEF architecture, it is the logical next step for these standards, which all certified EHRs are already required to include.

It is vital that SOGI be included in the required data classes for the USCDIv1. The non-inclusion of SOGI in the required data classes in the draft USCDIv1 makes TEFCA misaligned with the 2015 Edition Base EHR Definition certification criteria and the ISA. Inclusion of SOGI in USCDIv1 will significantly assist in achieving the interoperability goals of the 21st Century Cures Act. It would also echo the recommendations and policies set forth by numerous federal agencies and health care organizations that SOGI data are essential for improving the health of all people and for reducing health disparities that disproportionately burden sexual and gender minority populations.

Thank you for this opportunity to provide input.

Sincerely,

Kenneth Mayer, MD, FACP
Co-chair and Medical Research Director, The Fenway Institute
Director of HIV Prevention Research, Beth Israel Deaconess Medical Center
Professor of Medicine, Harvard Medical School

Jennifer Potter, MD
Co-chair, The Fenway Institute
Director of Women's Health, Fenway Health

Sean Cahill, PhD
Director of Health Policy Research
The Fenway Institute

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