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Dear Dr. Liburd and Dr. Mermin,

Thank you for all you are doing to keep us safe and healthy in these unprecedented times. We write to follow up on a conversation that you had with Sean Cahill, the Fenway Institute's Director of Health Policy Research, at the AIDS United Public Policy Committee meeting June 16, 2020. We at Fenway Health would like to engage the Health Equity Task Force created by the CDC Foundation and the Satcher Health Leadership Institute regarding sexual orientation and gender identity (SOGI) data collection and reporting in the COVID-19 pandemic. Dr. Liburd we were pleased to learn at the AIDS United meeting that you are the CDC's Chief Health Equity Officer for the COVID-19 response and a member of this Task Force.

Our goal in engaging the Task Force is to increase awareness of the potentially disproportionate impact of COVID-19 on LGBTQ populations and the importance of collecting and reporting SOGI data in real time to understand how LGBTQ disparities intersect with race/ethnicity and other demographic variables. As you know,

[The] Health Equity Task Force (HETF) [is] devoted to monitoring and assessing the disparate impacts on vulnerable populations, including, but not limited to racial/ethnic minorities, people living with disabilities, and those of lower socioeconomic status. A COVID-19 data consortium will be created to ensure the standardization of COVID-19 data at the national, state and local level.

One of the program's four key components is to:

Develop standardized, evidence-based best practices for developing socio-culturally responsive resources and provide technical assistance to local and state health organizations to improve their COVID-19 responses, data collection, reporting, planning, mitigation strategies, screening and contact tracing.¹

¹ CDC Foundation (2020, June 16). CDC Foundation and Satcher Health Leadership Institute Partner To Address COVID-19 Health Inequities. <https://www.cdcfoundation.org/pr/2020/satcher-health-leadership-institute-address-health-inequities>

The Fenway Institute at Fenway Health would welcome an opportunity to work with the Health Equity Task Force to develop standards and guidance for collecting and reporting SOGI data in SARS-CoV-2 testing and treatment for COVID-19 disease.

Why we need SOGI data collection and reporting related to COVID-19

It is vital that governments and public health experts have a clear picture of the disparate risks and impacts of the novel coronavirus on LGBTQ people to inform public health efforts. There are many reasons to believe that LGBTQ people may be disproportionately vulnerable to infection by the novel coronavirus and to complications should they develop COVID-19. This is especially true of Black, Latinx and indigenous LGBTQ people and LGBTQ older adults.

According to a Human Rights Campaign analysis of 2018 General Social Survey data, LGBTQ people disproportionately work in jobs that are considered essential: 40% work in restaurants/food services, health care, education, and retail, compared to 22% of non-LGBTQ individuals. They may therefore be more likely to be exposed to the coronavirus. Additionally, LGBTQ people suffer economic disparities that place many in living environments that may make it harder to maintain social distancing.² According to the Williams Institute at UCLA School of Law, 22% of LGBT people in the U.S. are poor, compared to 16% of straight cisgender people.³ LGBT people of color, bisexuals, and transgender people are more likely to be poor than other LGBT people. We also know that LGBTQ people are more likely to live in urban areas, where physical distancing measures are harder to maintain.

LGBTQ people are more likely to have some of the underlying health conditions that correlate with increased vulnerability to COVID-19-related health complications and fatalities. These include higher rates of cardiovascular disease, cancer, obesity, diabetes, and HIV/AIDS.⁴ A 2017 Center for American Progress survey found that 65% of LGBTQ people have chronic conditions.⁵ Lesbian and bisexual women are more likely than heterosexual women to be overweight or obese.⁶ There is also emerging research about higher rates of sedentarism, pre-

² Whittington C, Hadfield K, Calderón C (2020, March). *The lives and livelihoods of many in the LGBTQ community are at risk amidst COVID-19 crisis*. Washington, DC: Human Rights Campaign Foundation.

³ Badgett, Choi, Wilson (2019). *LGBT poverty in the United States: A study of differences between sexual orientation and gender identity groups*. UCLA School of Law, The Williams Institute. <https://williamsinstitute.law.ucla.edu/wp-content/uploads/National-LGBT-Poverty-Oct-2019.pdf>

⁴ Cahill S and Wang T (2019, June). Quality Innovation Network, Quality Improvement Organizations (QIN-QIO) Sharing Call: “Reducing chronic disease and health disparities in diverse LGBT populations.” National webinar.

⁵ Baker K, Singh S, Mirza SA, and Laura E. Durso (2017, July 6). *The Senate Health Care Bill Would Be Devastating for LGBTQ People*. Washington, DC: Center for American Progress. <https://www.americanprogress.org/issues/lgbtq-rights/news/2017/07/06/435452/senate-health-care-bill-devastating-lgbtq-people/>

⁶ Boehmer U, Bowen DJ, Bauer GR. (2007). Overweight and obesity in sexual minority women: Evidence from population-based data. *Am J Public Health* 97:1134–1140.

diabetes, and diabetes among LGBTQ youth, which could lead to diabetes later in life.⁷ LGBTQ older adults experience higher rates of disability than heterosexual, cisgender older adults.⁸

LGBTQ people across the age spectrum are more likely to smoke⁹ and vape,¹⁰ and to use substances.¹¹ Higher rates of tobacco and substance use are related to experiences of stigma, minority stress, and social anxiety. These disparities intersect with racial and ethnic health disparities. All of these conditions and risk behaviors could increase the vulnerability of LGBTQ people if they are exposed to SARS-CoV-2.

For these reasons, our health system, including the Department of Health and Human Services and the Centers for Disease Control and Prevention, should systematically collect and report sexual orientation and gender identity (SOGI) data in real time in relation to COVID-19. This would be consistent with the CDC's recommendations for seven of 10 essential public health services:

Of the CDC's 10 essential services that every public health system must deliver, at least seven relate to the collection and analysis of data. They include:

- monitoring community health status;
- diagnosing and investigating health problems and health hazards in the community;
- mobilizing community partnerships and action to identify and solve health problems;
- informing, educating, and empowering people about health issues;
- developing policies and plans that support individual and community health efforts;
- evaluating the effectiveness of public health initiatives; and
- conducting research for new insights and innovative solutions.¹²

Are LGBTQ people more likely to develop complications from COVID-19? Are they more likely to die? Are LGBTQ Black people most at risk? What about LGBTQ older adults and long-term survivors living with HIV in the U.S., most of whom are LGBTQ? These are critically important questions. We need our nation's public health response system to systematically collect SOGI data to understand if LGBTQ people face increased risks of acquiring the novel coronavirus, how LGBTQ people are experiencing COVID-19, and how LGBTQ disparities intersect with racial and ethnic disparities in COVID-19 risks and outcomes. This data will help

⁷ Beach L, Turner B, Felt D, et al. (2018). Risk factors for diabetes are higher among non-heterosexual US high school students. *Pediatric Diabetes*, 19(7):1137-1146.

⁸ Fredriksen-Goldsen, K. I., Kim, H.-J., Emlert, C. A., Muraco, A., Erosheva, E. A., Hoy-Ellis, C. P., . . . Petry, H. (2011). *The aging and health report: Disparities and resilience among lesbian, gay, bisexual, and transgender older adults*. Seattle: University of Washington.

⁹ Lee JG, Griffin GK, Melvin CL. (2009). Tobacco use among sexual minorities in the USA, 1987 to May 2007: A systematic review. *Tob Control* 18:275–282.

¹⁰ Washington R, Cahill S. (2019, June). "Do e-cigarettes represent a harm reduction approach for the LGBT community? How do we reduce disparities in use?" National LGBTQ Health Conference, Emory University, Atlanta. Concurrent session—substance use.

¹¹ Song YS, Sevelius JM, Guzman R, Colfax G. (2008). Substance use and abuse. *The Fenway Guide to Lesbian, Gay, Bisexual and Transgender Health*. Philadelphia: American College of Physicians. 2008. 209-247.

¹² CDC (last updated May 21, 2020). The Public Health System & the 10 Essential Public Health Services. <https://www.cdc.gov/publichealthgateway/publichealthservices/essentialhealthservices.html>

ensure that prevention efforts, testing, and care services are effectively meeting the needs of LGBTQ people.

SOGI data collection would be consistent with a decade of federal initiatives

Over the past decade, a number of federal agencies and initiatives have encouraged SOGI data collection in health care settings:

- 2010 Healthy People 2020, our nation's health promotion and prevention strategy, makes promoting SOGI data collection to help understand and eliminate disparities a key priority. It states, “In order to effectively address LGBT health issues, we need to securely and consistently collect SOGI information in national surveys and health records. This will allow researchers and policy makers to accurately characterize LGBT health and disparities.”¹³
- The 2011 Institute of Medicine Report on LGBT Health called for SOGI questions to be included in the Meaningful Use Program (a CMS/ONC-led incentive program to promote the shift to Electronic Health Records) and added to more health and demographic surveys.¹⁴
- In 2015, ONC adopted SOGI standards as required fields in the “demographics” section of the 2015 Edition Base Electronic Health Record (EHR) Definition certification criteria, making SOGI part of all Certified Electronic Health Record Technology (CEHRT) products.¹⁵
- SOGI have also been included in the Interoperability Standards Advisory since it was first published in 2015.¹⁶ SOGI standards have achieved steadily increasing and high levels of maturity and adoption since 2015, as reflected in the 2020 reference edition of ONC’s Interoperability Standards Advisory.¹⁷
- In 2015 the Centers for Medicare and Medicaid Services encourage the collection and use of SOGI data to improve quality of care in their *CMS Equity Plan for Medicare Beneficiaries*.¹⁸

In addition to these government agency actions, in 2011 the Joint Commission called for SOGI data collection.¹⁹ The American Medical Association (2017)²⁰ and other professional associations have adopted formal positions supporting SOGI data collection in health care.

¹³ <https://www.healthypeople.gov/2020/topics-objectives/topic/lesbian-gay-bisexual-and-transgender-health>

¹⁴ Cahill S, Baker K, Deutsch M, Keatley J, Makadon H. (2016). Inclusion of sexual orientation and gender identity in Stage 3 Meaningful Use guidelines a huge step forward for LGBT health. *LGBT Health*. 2016 Apr;3(2):100-2.

¹⁵ Ibid.

¹⁶ https://www.healthit.gov/isa/sites/default/files/2015interoperabilitystandardsadvisory01232015final_for_public_comment.pdf

¹⁷ <https://ecqi.healthit.gov/onc-interoperability-standards-advisory-isa-2020-reference-edition-now-available>

¹⁸ Cahill, Baker, Deutsch et al., 2016.

¹⁹ file:///C:/Users/scahill/Downloads/LGBTFieldGuide_WEB_LINKED_VERpdf.pdf

²⁰ <https://www.ama-assn.org/system/files/2019-07/lgbtq-activities.pdf>

Health centers are collecting, reporting, and using SOGI data to improve quality of care and our understanding of LGBTQ disparities. An increasing number of hospitals and private practices are as well. Inclusion of SOGI data in Electronic Health Records is the industry norm.

How HHS and CDC can promote SOGI data collection related to COVID-19

There are several ways that the federal government can encourage and promote SOGI data collection and reporting:

1) Issue guidance and data reporting guidelines or requirements.

Organizations testing individuals for SARS-CoV-2 should ask everyone about their SOGI as standard demographic variables when they register to take the test. This is often done through an online portal. We do this at Fenway Health in Boston. Testing companies like Quest Diagnostics should be encouraged to encourage those sending test samples to them to provide SOGI data along with other demographic data. This is important because the private testing companies report a large proportion of the coronavirus test results to local and state health departments.

Federally qualified health centers that are testing for SARS-CoV-2 report their results to HRSA and to their state health department. They should be encouraged or required to collect SOGI data from the individual testing, or to match the test results with the patient's EHR data, which should include SOGI data. They should then report this information to local, state and federal authorities.

We were disappointed that the HHS COVID-19 laboratory data guidance released June 4, 2020 does not require or even just encourage the reporting of sexual orientation and gender identity data.²¹ We are especially disappointed given the awareness of key federal health officials of the disproportionate impact of HIV on gay and bisexual men and transgender women, especially Black and Latinx gay and bisexual men and transgender women, and of other health disparities and barriers to accessing care affecting LGBTQ people. We wrote a letter, co-signed by several dozen LGBTQ and HIV organizations, to Secretary Azar and Assistant Secretary Giroir urging HHS to revise these test reporting guidelines to encourage or require the collection and reporting of SOGI data.

2) Match SARS-CoV-2 case reports to EHRs

Increasingly EHRs collect and track SOGI data from patients. All federally qualified health centers must collect SOGI from their adult patients and report to the federal government. This represents approximately 20 million diverse patients. Hundreds of hospitals, health systems, and private practices also collect SOGI data from patients. CDC should encourage state and local health departments to match coronavirus case reports to EHRs, like Pennsylvania is doing,²² and report this publicly to understand the impact on LGBTQ people.

²¹ HHS (2020, June 4). COVID-19 Pandemic Response, Laboratory Data Reporting: CARES Act Section 18115. <https://www.hhs.gov/sites/default/files/covid-19-laboratory-data-reporting-guidance.pdf>

²² Governor Tom Wolf (2020, May 13). Gov. Wolf Announces Inclusion of Gender Identity, Sexual Orientation or Expression in COVID-19 Data Collection (press release). <https://www.governor.pa.gov/newsroom/gov-wolf-announces-inclusion-of-gender-identity-sexual-orientation-or-expression-in-covid-19-data-collection/>

3) Train contract tracers to collect missing SOGI data

Contract tracers can ask newly diagnosed individuals about SOGI as well as other important demographic information. Contact tracers would have to be trained in how to ask these questions, as other health workers have been trained. Online training modules and resources are available at the National LGBTQIA+ Health Education Center (<https://www.lgbtqihealtheducation.org/>).

Whether it is contract tracers who ask SOGI questions or if patients are asked when they register for a coronavirus test, SOGI questions should be asked in a manner that is voluntary for individuals. Privacy and confidentiality protections that apply to other personal health information also apply to SOGI data.

It is also important to ensure that the health care workforce is trained to provide culturally responsive and affirming care for SGM patients. This includes staff testing people for SARS-CoV-2, providing care to patients with COVID-19, and conducting contact tracing to notify people who may have come into contact with the individual who tested positive for SARS-CoV-2. It is important that these staff be trained in using the correct names and pronouns for transgender and gender-diverse people; this information may differ from that listed on their official identity documents. Staff should also be respectful and nonjudgmental when conducting contact tracing for same-sex sexual partners.

Please work with us to address these important health equity issues

It is unfortunate that, in the midst of the greatest public health crisis of our lifetimes, our government and public health system are responding without data on how COVID-19 is affecting LGBTQ people. This need not be the case.

We would welcome the opportunity to discuss these issues with you and other members of the Health Equity Task Force in greater detail. We think that would help the Task Force in its efforts to develop best practices for improving COVID-19 data collection and reporting, as well as contact tracing, and support CDC's efforts to provide technical assistance to local and state health organizations.

The nation's public health response system—at the local, state, and national levels—needs to systematically collect SOGI data to understand how LGBTQ people are experiencing COVID-19 and how LGBTQ disparities intersect with racial/ethnic disparities in COVID-19 outcomes, as well as to ensure that prevention, testing, and care services are effectively meeting the needs of LGBTQ people. We hope that we can discuss these important health equity issues with you soon and work together to address them.

To schedule a conversation on these issues, please contact Sean Cahill, PhD, Director of Health Policy Research at the Fenway Institute, at scahill@fenwayhealth.org or 646-761-6639.

Thank you.

Sincerely,

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