

September 16, 2020

Michael Curry

Deputy CEO and General Counsel at
Massachusetts League of Community
Health Centers

Dr. Assaad Sayah

CEO, Cambridge Health Alliance; Commissioner of
Public Health, City of Cambridge; Assistant
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Dear Michael Curry and Dr. Assaad Sayah,

Thank you for the important work the Task Force is doing to address health inequities exacerbated by the COVID-19 pandemic. Removing barriers and increasing access to quality, equitable health care services and treatment are critical actions to determine and rectify major disparities in health care during this crisis. In order to address the disproportionate health risks that the LGBTQ population faces, we request that the task force include sexual orientation and gender identity (SOGI) data collection and reporting in real time. This must be done in order to understand how LGBTQ disparities in the COVID-19 pandemic intersect with race/ethnicity and other factors, and assess the impacts on all vulnerable populations.

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.¹ 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.² 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.

¹ 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.

² 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>

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.³ A 2017 Center for American Progress survey found that 65% of LGBTQ people have chronic conditions.⁴ Lesbian and bisexual women are more likely than heterosexual women to be overweight or obese.⁵ There is also emerging research about higher rates of sedentarism, pre-diabetes, and diabetes among LGBTQ youth, which could lead to diabetes later in life.⁶ LGBTQ older adults experience higher rates of disability than heterosexual, cisgender older adults.⁷

LGBTQ people across the age spectrum are more likely to smoke⁸ and vape,⁹ and to use substances.¹⁰ 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 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, several of which 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; and
- conducting research for new insights and innovative solutions.¹¹

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 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 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

³ 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.

⁴ 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/>

⁵ Azagba S, Shan L, Latham K (2019). Overweight and Obesity among Sexual Minority Adults in the United States. *Int J Environ Res Public Health*. 2019;16(10):1828.

⁶ 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.

⁷ Fredriksen-Goldsen, K. I., Kim, H.-J., Emlet, 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.

⁸ 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.

⁹ 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.

¹⁰ 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.

¹¹ CDC (last updated May 21, 2020). The Public Health System & the 10 Essential Public Health Services. <https://www.cdc.gov/publichealthgateway/publichealthservices/essentialhealthservices.html>

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

- 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.¹²
- 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.¹³
- 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.¹⁴
- SOGI have also been included in the Interoperability Standards Advisory since it was first published in 2015.¹⁵ 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.¹⁶
- 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*.¹⁷

In addition to these government agency actions, in 2011 the Joint Commission called for SOGI data collection.¹⁸ The American Medical Association (2017)¹⁹ and other professional associations have adopted formal positions supporting SOGI data collection in health care.

Several states are taking the lead on SOGI data collection in the COVID-19 pandemic, including Pennsylvania, California,²⁰ Rhode Island (SO only), and the District of Columbia.²¹ California is requiring all health care providers and labs to collect and report to the state health department SOGI data in COVID-19 cases and other reportable diseases. The Massachusetts Department of Public Health is adding SOGI fields to the Mass. Virtual Epidemiologic Network (MAVEN), and is on the verge of releasing SOGI data standards. But it could do more to encourage the collection and reporting of SOGI data in the COVID-19 pandemic here in the Commonwealth. **It would be most helpful if Mass. DPH would publish guidance encouraging health care providers and testing entities to report SOGI data in COVID-19 testing and care.**

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.

There are several ways that the Task Force can encourage and promote SOGI data collection and reporting:

¹² <https://www.healthypeople.gov/2020/topics-objectives/topic/lesbian-gay-bisexual-and-transgender-health>

¹³ 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.

¹⁴ Ibid.

¹⁵ https://www.healthit.gov/isa/sites/default/files/2015interoperabilitystandardsadvisory01232015final_for_public_comment.pdf

¹⁶ <https://ecqi.healthit.gov/onc-interoperability-standards-advisory-isa-2020-reference-edition-now-available>

¹⁷ Cahill, Baker, Deutsch et al., 2016.

¹⁸ file:///C:/Users/scahill/Downloads/LGBTFieldGuide_WEB_LINKED_VERpdf.pdf

¹⁹ <https://www.ama-assn.org/system/files/2019-07/lgbtq-activities.pdf>

²⁰ <https://www.nytimes.com/2020/07/29/us/california-coronavirus-demographics.html>

²¹ Cahill S, Grasso C, Keuroghlian A, Sciortino C, Mayer K (2020, September). Sexual and Gender Minority Health in the COVID-19 Pandemic: Why Data Collection and Combatting Discrimination Matter Now More than Ever. *Am J Public Health*. Vol. 110, No. 9. 1360-1361.

1) Include guidance and data reporting guidelines or requirements in your final report.

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 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.

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. The Task Force report should require 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.

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.lgbtqiahealtheducation.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 Sexual and Gender Minority (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.

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/>

We would welcome the opportunity to discuss these issues with you and other members of the Health Equity Task Force in greater detail. Please consider us a resource in any efforts to develop best practices for improving COVID-19 SOGI data collection and reporting.

The 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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