June 12, 2020

The Honorable Alex Azar
Secretary
U.S. Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

Admiral Brett Giroir, M.D.
Assistant Secretary for Health
U.S. Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

Dear Secretary Azar and Assistant Secretary Giroir,

We write to express strong disappointment that the HHS COVID-19 laboratory data guidance released June 4 does not require the reporting of sexual orientation and gender identity data (https://www.hhs.gov/sites/default/files/covid-19-laboratory-data-reporting-guidance.pdf). We are especially disappointed given your awareness 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. It is vital that governments and public health experts have a clear picture of the disparate risks and impacts of the coronavirus (SARS-CoV-2) 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] We also know that LGBTQ people are more likely to live in urban areas, where physical distancing measures are harder to maintain.

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[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 smoke[8] 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, HHS should systematically collect and report sexual orientation and gender identity (SOGI) data in real time in relation to COVID-19, consistent with the Centers for Disease Control's recommendations for seven of 10 essential public health services.[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

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[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] 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.

[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] 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. https://www.cdc.gov/publichealthgateway/publichealthservices/essentialhealthservices.html

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 COVID-19, 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.

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."[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 (former JC) 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.

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[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

Health centers are collecting, reporting, and using SOGI data to improve quality of care and improve 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 is no reason why coronavirus testers cannot collect SOGI data and report to public health authorities on the sexual orientation and gender identity of people tested along with race/ethnicity, age, place of residence, and other demographic factors.

We are deeply concerned and disappointed 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. Please revise the HHS COVID-19 laboratory data guidance released June 4 to require the collection and reporting of sexual orientation and gender identity data in coronavirus (SARS-CoV-2) and COVID-19 testing in a manner that is voluntary for individuals and sufficiently protects privacy and confidentiality. Should you have any questions or seek assistance in addressing this important public health concern, 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,

The Fenway Institute, Ellen LaPointe, CEO

AIDS Action Baltimore, Lynda Dee, Executive Director

AIDS Alabama, Matt Pagnotti, Director of Policy & Advocacy

APLA Health, Craig E. Thompson, CEO

AVAC, Kevin Fisher, Policy Director

Campus Pride, Shane Windmeyer, Executive Director

Cascade AIDS Project, Tyler TerMeer, CEO

Center for Health Law and Policy Innovation, Robert Greenwald, Faculty Director

CenterLink: The Community of LGBT Centers, Denise Spivak, Policy Manager

Community Education Group, A. Toni Young, Founder and Executive Director

Ethos, Valerie K. Frias, CEO

Equality California, Valerie Ploumpis, National Policy Director

Equality North Carolina, Ames Simmons, Policy Director

GLBTQ Legal Advocates & Defenders (GLAD), Gary Buseck, Legal Director

GLMA: Health Professionals Advancing LGBTQ Equality, Hector Vargas, Executive Director

HIV Dental Alliance, David Reznik, President

Howard Brown Health, Andie Baker, VP Center for Education, Research and Advocacy

Human Rights Campaign, David Stacy, Government Affairs Director

Lambda Legal, Jennifer Pizer, Director of Law and Policy

LGBT Aging Project, Lisa Krinsky, Director

LGBT Elders of Color, Paul Glass, President

LifePath, Lynne Feldman, Director of Community Services

Los Angeles LGBT Center, Aaron Fox, Director of Government Relations

Massachusetts Councils on Aging, David P. Stevens, Executive Director

Massachusetts Home Care, Lisa Gurgone, Executive Director

Massachusetts Senior Care Association/Foundation, William Bogdanovich, Foundation Board President

MassEquality, Tanya Neslusan, Executive Director

NASTAD, Emily McCloskey, Director, Policy & Legislative Affairs

National Coalition for LGBT Health, Brian Hujdich, Executive Director

National Equality Action Team, Brian Silva, Founder and Executive Director

PFLAG National, Diego Miguel Sanchez, Director of Advocacy, Policy & Partnerships

Prism Health, Tyler TerMeer, CEO

San Francisco AIDS Foundation, Ernest Hopkins, Senior Strategist and Advisor

Silver State Equality – Nevada, Valerie Ploumpis, National Policy Director

The Trevor Project, Sam Brinton, VP of Advocacy and Government Affairs

Transgender Legal Defense and Education Fund, David Brown, Legal Director

Treatment Action Group, Mark Harrington, Executive Director