

To: Biden Harris Administration COVID-19 Health Equity Task Force
From: Sean Cahill, PhD, Director of Health Policy Research
Date: April 9, 2021
Re: Sexual orientation and gender identity (SOGI) and intersex data collection and reporting in COVID-19 testing, care and vaccination

Hello Madame Chair and Task Force members. I am Sean Cahill, Director of Health Policy Research at The Fenway Institute and Affiliate Associate Clinical Professor of Health Sciences at Northeastern University. I'm speaking on behalf of the LGBTQI Federal Health Policy Roundtable.

We encourage the Biden-Harris Administration to issue federal guidance requiring the collection and reporting of data on sexual orientation, gender identity, and intersex status in COVID-19 testing, care and vaccination.

Why is this important?

First, LGBTQI people may be more vulnerable to infection with the novel coronavirus.

LGBTQ people are nearly twice as likely to work in frontline jobs like retail, food services, health care, and education.¹

Many LGBTQI people live in urban areas, live in dense congregate housing, and use public transportation, where social distancing is difficult.

LGBT people are more likely to be low-income, especially bisexual women, transgender people, and people of color.²

A recent Williams Institute analysis of Axios/Ipsos survey data found that LGBT people of color were more likely than straight, cisgender people of color to test positive for COVID-19, and twice as likely to test positive for COVID-19 than LGBT White people.¹

Second, LGBT people are more likely to have chronic conditions such as diabetes,³ asthma,⁴ obesity, and cardiovascular disease,⁵ and risk factors like smoking,

¹ Sears, B. Conron, K.J., & Flores, A.J. (2021). *The Impact of the Fall 2020 Surge of the COVID-19 Pandemic on LGBT Adults in the US*. Los Angeles, CA: The Williams Institute, UCLA.

vaping,⁶ and substance use disorder,⁷ that may put them at risk for complications from COVID-19.

Third, LGBTQ people experience discrimination in health care as well as in employment, housing and other settings.⁸ This discrimination has negative physical and mental health effects, and serves as a barrier to accessing health care.⁹ Sexual minority women, transgender people, and LGBT people of color are less likely to access routine, preventive care due to discrimination and lower rates of health insurance.¹⁰ This may inhibit their ability to access COVID-19 testing, care, and vaccination.

LGBTQI people must be included in vaccine dissemination plans, and sexual orientation and gender identity data--SOGI data—must be collected to ensure equitable vaccine uptake.¹¹ LGBTQI people experience medical mistrust, which could affect willingness to get the vaccine.

Many older people experience medical mistrust because in their youth the medical establishment pathologized same-sex behavior and gender diversity, subjecting them to shock therapy or worse.¹²

Intersex people mistrust the medical community due to abuses many experience in childhood and adulthood.¹³

A recent analysis in the journal *Vaccine* found that Black and Native American men who have sex with men were less willing than White and Latino MSM to get vaccinated for COVID-19, while Asian American MSM were more likely to get vaccinated.¹⁴

The Biden-Harris Administration should issue federal guidance that, at a minimum, encourages SOGI + intersex data collection and reporting in COVID-19 testing, care and vaccination uptake. This could come from CDC or somewhere else in HHS. The CDC COVID-19 case report form needs to add SOGI questions and change its sex question. Right now the sex question response options on that form are “male, female, other, unknown.”¹⁵ These are not affirming, and miss an opportunity to understand how this pandemic is affecting LGBTQI people.

It is also imperative that the National COVID Cohort Collaborative (N3C), a project of the National Center for Advancing Translational Sciences, add SOGI + intersex to its COVID-19 Clinical Data Warehouse Data Dictionary. By not

including SOGI + intersex, N3C does not allow for research on LGBTQI populations' experiences with COVID-19.

In the midst of the worst global pandemic of our lifetimes, our federal government and most state governments are not collecting and reporting SOGI data so that we know how COVID-19 is affecting LGBTQI people, including LGBTQI people of color and elders. Given the Biden-Harris Administration's commitment to LGBTQI equality and health equity, we hope that the Biden Harris Administration will issue federal guidance soon. I am heartened by Dr. Khaldun's presentation today. We hope to work with the Task Force and the Data, Analytics and Research Committee to help address this important data equity issue.

Thank you.

¹ Whittington C, Hadfield K, Calderón C. *The lives and livelihoods of many in the LGBTQ community are at risk amidst COVID-19 crisis*. Washington, DC: Human Rights Campaign. 2020. Available at:

<https://www.hrc.org/resources/the-lives-and-livelihoods-of-many-in-the-lgbtq-community-are-at-risk-amidst>

² Badgett MVL, Choi SK, Wilson BDM (2019, Oct.). *LGBT Poverty in the United States: A Study of Differences Between Sexual Orientation and Gender Identity Groups*. Los Angeles, CA: UCLA School of Law, The Williams Institute. <https://williamsinstitute.law.ucla.edu/wp-content/uploads/National-LGBT-Poverty-Oct-2019.pdf>

³ Beach LB, Elasy TA, Gonzales G. Prevalence of Self-Reported Diabetes by Sexual Orientation: Results from the 2014 Behavioral Risk Factor Surveillance System. *LGBT Health*. 2018 Feb/Mar;5(2):121-130.

⁴ Karen I. Fredriksen-Goldsen, Hyun-Jun Kim, Chengshi Shui, and Amanda E. B. Bryan, 2017: Chronic Health Conditions and Key Health Indicators Among Lesbian, Gay, and Bisexual Older US Adults, 2013–2014. *American Journal of Public Health* 107, 1332_1338.

⁵ Fredriksen-Goldsen KI, Kim H-J, Emlet CA, et al. *The Aging and Health Report: Disparities and Resilience Among Lesbian, Gay, Bisexual, and Transgender Older Adults*. Seattle: University of Washington; 2011.

⁶ McCabe SE, Matthews AK, Lee JGL, Veliz P, Hughes TL, Boyd CJ. Tobacco use and sexual orientation in a national cross-sectional study: age, race/ethnicity, and sexual identity—attraction differences. *Am J Prev Med*. 2018;54(6):736–745.

⁷ National Institute on Drug Abuse (no date; accessed March 23, 2021). Substance use and SUDs in LGBTQ* populations. <https://www.drugabuse.gov/drug-topics/substance-use-suds-in-lgbtq-populations>

⁸ Ahmed Mirza, Shabab and Rooney, Caitlin (2018). *Discrimination Prevents LGBTQ People from Accessing Health Care*. Washington, DC: Center for American Progress.

⁹ Reisner SL, White Hughto JM, Dunham E, Heflin K, Begenyi JB, Coffey-Esquivel J, Cahill S (2015). Legal protections in public accommodations settings: A critical public health issue for transgender and gender nonconforming people. *Milbank Quarterly*. 1-32.

¹⁰ American Cancer Society. 2020. *Cancer Facts for Lesbian and Bisexual Women*. <https://www.cancer.org/healthy/find-cancer-early/womens-health/cancer-facts-for-lesbians-and-bisexual-women.html#:~:text=Studies%20suggest%20that%20some%20lesbian,and%20cervical%20cancer%20screening%20tests.>

¹¹ <https://fenwayhealth.org/wp-content/uploads/12.18.20-LGBTQI-Data-Vaccination-Letter.pdf>

¹² Blakemore E. (no date). Gay Conversion Therapy's Disturbing 19th-Century Origins. HISTORY. Accessed December 17, 2020. <https://www.history.com/news/gay-conversion-therapy-origins-19th-century>

¹³ *Covid-19 Survey Report*. OII Europe. Published December 9, 2020. Accessed December 17, 2020. <https://oiieurope.org/covid-19-survey-report/>

¹⁴ Teixeira da Silva D, Biello K, Lin WY, et al. COVID-19 Vaccine Acceptance among an Online Sample of Sexual and Gender Minority Men and Transgender Women. *Vaccines* 2021, 9, 204.

¹⁵ <https://www.cdc.gov/coronavirus/2019-ncov/downloads/pui-form.pdf>