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White House Office of Science and Technology Policy
Interagency Working Group on Equitable Data
Subcommittee on Sexual Orientation, Gender Identity, and Variations in Sex Characteristics
(SOGI) Data

Request for Information: Federal Evidence Agenda on LGBTQI+ Health Equity

submitted via: equitabledata@ostp.eop.gov

Dear Subcommittee Members,

The Fenway Institute at Fenway Health submits the following comment regarding the Office of Science and Technology Policy's Request for Information: Federal Evidence Agenda on LGBTQI+ Health Equity published August 19, 2022. The Fenway Institute is the research, education and training, and policy arm of Fenway Health, a federally qualified health center and Ryan White Part C HIV clinic in Boston, Massachusetts. We provide care to about 35,000 patients every year. Half of our patients are LGBTQIA+, and about 5400 are transgender and nonbinary. About 2,300 of our patients are people living with HIV. Our comments address the questions in the RFI.

1. What disparities faced by LGBTQI+ people are not well-understood through existing Federal statistics and data collection? Are there disparities faced by LGBTQI+ people that Federal statistics and other data collections are currently not well-positioned to help the Government understand?

It is critically important that the Biden-Harris Administration take steps to collect SOGI data in big data systems that currently ignore LGBTQI+ people. These include:

Cardiovascular and stroke registries: The National Cardiovascular Data Registry, Paul Coverdell National Acute Stroke Registry, and STEMI (Segment Elevation Myocardial Infarction) registries should all collect and regularly report SOGI data. A broad body of research

has documented striking disparities in cardiovascular disease^{1,2,3,4} and hypertension^{5,6} affecting LGBT people. We must start collecting SOGI data in these important public health registries that we all pay taxes to support.

Cancer registries: The National Cancer Institute’s Surveillance, Epidemiology, and End Results (SEER) Program should include SOGI, and the CDC’s National Program of Cancer Registries should require that states collect and report SOGI. Research also shows a higher prevalence of a number of cancers among LGBT people.⁷

The US Standard Certificate of Death: US Standard Certificate of Death should include SOGI. We know that LGBTQ+ people experience disparities in substance use⁸ and other health risk factors including smoking,^{9,10,11} vaping,¹² and suicidality,¹³ but we don’t capture these data in death.

Deaths from overdose have surged since the beginning of the COVID-19 pandemic. There is a real need to create spaces for substance use disorder (SUD) services and make sure that they are welcoming to LGBTQIA+ and BIPOC populations, as these are disproportionately

¹ 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.

² Caceres BA, Makarem N, Hickey KT, Hughes TL. Cardiovascular Disease Disparities in Sexual Minority Adults: An Examination of the Behavioral Risk Factor Surveillance System (2014-2016). *Am J Health Promot*. 2019 May;33(4):576-585.

³ Caceres BA, Jackman KB, Edmondson D, Bockting WO. Assessing gender identity differences in cardiovascular disease in US adults: an analysis of data from the 2014-2017 BRFSS. *J Behav Med*. 2020 Apr;43(2):329-338.

⁴ Nokoff NJ, Scarbro S, Juarez-Colunga E, Moreau KL, Kempe A. Health and Cardiometabolic Disease in Transgender Adults in the United States: Behavioral Risk Factor Surveillance System 2015. *J Endocr Soc*. 2018 Mar 5;2(4):349-360.

⁵ Caceres BA, Brody AA, Halkitis PN, Dorsen C, Yu G, Chyun DA. Sexual Orientation Differences in Modifiable Risk Factors for Cardiovascular Disease and Cardiovascular Disease Diagnoses in Men. *LGBT Health*. 2018;5(5):284-294.

⁶ Jackson CL, Agénor M, Johnson DA, Austin SB, Kawachi I. Sexual orientation identity disparities in health behaviors, outcomes, and services use among men and women in the United States: a cross-sectional study. *BMC Public Health*. 2016;16(1):807.

⁷ Cahill SR. Legal and Policy Issues for LGBT Patients with Cancer or at Elevated Risk of Cancer. *Semin Oncol Nurs*. 2018 Feb;34(1):90-98.

⁸ 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>

⁹ Caceres BA, Makarem N, Hickey KT, et al., 2019.

¹⁰ Lunn MR, Cui W, Zack MM, Thompson WW, Blank MB, Yehia BR. Sociodemographic Characteristics and Health Outcomes Among Lesbian, Gay, and Bisexual U.S. Adults Using Healthy People 2020 Leading Health Indicators. *LGBT Health*. 2017 Aug;4(4):283-294.

¹¹ Alzahrani T, Nguyen T, Ryan A, Dwairy A, McCaffrey J, Yunus R, Forgione J, Krepp J, Nagy C, Mazhari R, Reiner J. Cardiovascular Disease Risk Factors and Myocardial Infarction in the Transgender Population. *Circ Cardiovasc Qual Outcomes*. 2019 Apr;12(4):e005597.

¹² 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.

¹³ Hafeez H, Zeshan M, Tahir MA, Jahan N, Naveed S. Health Care Disparities Among Lesbian, Gay, Bisexual, and Transgender Youth: A Literature Review. *Cureus*. 2017 Apr 20;9(4):e1184. doi: 10.7759/cureus.1184. PMID: 28638747; PMCID: PMC5478215.

affected. Accurate SOGI data can provide critically needed data to inform culturally competent and responsive SUD treatment and harm reduction services.

CDC Data Modernization Initiative: The Biden-Harris Administration should also ensure that the CDC's Data Modernization Initiative, funded by \$500 million in funding from the CARES Act, makes LGBTQIA+ health equity a central goal, and prioritizes increasing and improving SOGI data collection in public health surveillance.

Older adults: There is a dearth of data affecting older LGBTQI+ people, including people in congregate living facilities such as nursing homes, long-term care, and assisted living. We'd also like to see SOGI data collection expanded in elder services, as we know that LGBT older adults are more in need of elder services, such as formal caregiving support, but may be less likely to access these services.¹⁴ Federal guidance could encourage and incentivize such data collection by Area Agencies on Aging, state and local aging departments, and service providers.

As more people with HIV are living longer, we have a growing number of long-term survivors (LTS) who are experiencing symptoms of pre-mature aging and need access to services earlier than age 65. An additional barrier to accessing the services is fear and stigma. Accurate SOGI data can help inform the development of targeted, culturally competent elder services, particularly home care.

COVID-19 testing, treatment, and vaccination: Since spring 2020,¹⁵ LGBTQI+ community organizations have been urging the federal government to issue federal guidance requiring the collection and reporting of data on sexual orientation, gender identity, and sex characteristics (SOGI) in COVID-19 testing, care and vaccination. This is important because 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.¹⁶ 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.¹⁷ A Williams Institute analysis of Axios/Ipsos survey data found that LGBT people of color were more likely

¹⁴ Cahill S. Community resources and government services for LGBT older adults and their families. Orel N, Fruhauf C (eds.). *The Lives of LGBT Older Adults: Understanding Challenges and Resilience*. Washington, DC: American Psychological Association, 2014. 141-170.

¹⁵ April 28, 2020 letter from Fenway Health, AIDS United, Center for American Progress, Human Rights Campaign, and San Francisco AIDS Foundation to Congressional leadership. <https://fenwayhealth.org/wp-content/uploads/4.29.20-letter-to-Speaker-Pelosi-Leader-McConnell-re-SOGI-nondisc-and-data-collection.pdf>; June 10, 2022 letter from Fenway Health to HHS leadership re: HHS COVID-19 laboratory data guidance released June 4, 2022. <https://fenwayhealth.org/wp-content/uploads/letter-to-HHS-COVID-data-guidance-.pdf>

¹⁶ 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>

¹⁷ 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>

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.¹⁸

LGBT people are more likely to have chronic conditions such as diabetes,¹⁹ asthma,²⁰ obesity, and cardiovascular disease,²¹ and risk factors like smoking, vaping,²² and substance use disorder,²³ that may put them at risk for complications from COVID-19. LGBTQ people experience discrimination in health care as well as in employment, housing and other settings.²⁴ This discrimination has negative physical and mental health effects, and serves as a barrier to accessing health care.²⁵ 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.²⁶ This may inhibit their ability to access COVID-19 testing, care, and vaccination.

LGBTQI+ people should be included in vaccine dissemination plans, and SOGI data must be collected to ensure equitable vaccine uptake.²⁷ 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.²⁸ Intersex people mistrust the medical community due to abuses many experience in childhood and adulthood.²⁹

¹⁸ 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.

¹⁹ 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.

²⁰ 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.

²¹ Fredriksen-Goldsen KI, Kim H-J, Emler CA, et al. *The Aging and Health Report: Disparities and Resilience Among Lesbian, Gay, Bisexual, and Transgender Older Adults*. Seattle: University of Washington; 2011.

²² 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.

²³ 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>

²⁴ Ahmed Mirza, Shabab and Rooney, Caitlin (2018). *Discrimination Prevents LGBTQ People from Accessing Health Care*. Washington, DC: Center for American Progress.

²⁵ 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.

²⁶ 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>.

²⁷ <https://fenwayhealth.org/wp-content/uploads/12.18.20-LGBTQI-Data-Vaccination-Letter.pdf>

²⁸ 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>

²⁹ *Covid-19 Survey Report*. OII Europe. Published December 9, 2020. Accessed December 17, 2020. <https://oiiEurope.org/covid-19-survey-report/>

The Biden-Harris Administration should issue federal guidance that, at a minimum, encourages SOGI 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.”³⁰ 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 to its COVID-19 Clinical Data Warehouse Data Dictionary. By not including SOGI, N3C does not allow for research on LGBTQI populations’ experiences with COVID-19. Also, COVID-NET, a network of 100 large hospitals meant to represent the US population, should collect and report SOGI in COVID-19 care, testing and vaccination. 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. The Biden-Harris Administration should also ensure that the CDC’s Data Modernization Initiative, funded by \$500 million in funding from the CARES Act, prioritizes increasing and improving SOGI data collection in public health surveillance.

2. Are there community-based or nonFederal statistics or data collection that could help inform the creation of the Federal Evidence Agenda on LGBTQI+ Equity? Are there disparities that are better understood through community based research than through Federal statistics and/or other data collection?

Yes. Many community-based organizations conduct important local research with important implications for LGBTQI+ people across the nation. An example is the recent study by the Fenway Institute and the LGBT Aging Project, *LGBT Aging 2025: Strategies for Achieving a Healthy and Thriving LGBT Older Adult Community in Massachusetts*.³¹ This study is based on nine listening sessions with LGBT older adults convened across Massachusetts in 2019 and 2020. Five were in person and four were virtual, something necessitated by the onset of COVID-19. The study also analyzes Massachusetts Behavioral Risk Factor Surveillance System data comparing older adults who are LGBT to those who are straight and cisgender.

Key themes that came up in the listening sessions were:

- Strong anti-LGBT prejudice in rural Massachusetts, and from age peers across the Commonwealth
- Social isolation and lack of connection
- Mental health needs specific to social isolation during the COVID-19 lockdown
- The need for ongoing services and mental health care for LGBT widows and widowers, especially those in rural areas
- The need for social activities that create a sense of community and belonging
- Transportation needs, especially in rural Massachusetts

³⁰ <https://www.cdc.gov/coronavirus/2019-ncov/downloads/pui-form.pdf>

³¹ Cahill S (2020). *LGBT Aging 2025: Strategies for Achieving a Healthy and Thriving LGBT Older Adult Community in Massachusetts*. Boston: The Fenway Institute, LGBT Aging Project.
<https://fenwayhealth.org/wp-content/uploads/LGBT-Aging-2025-Report-December-2020.pdf>

- Anti-LGBT discrimination in assisted living
- Gender-based sexual harassment (deliberate, repeated misgendering of cisgender lesbian women) in businesses and health care facilities in the Berkshires
- The centrality of trauma in people's lives
- The need to address racism within the LGBT community
- A dearth of LGBT-competent and -affirming health care in rural Massachusetts
- Struggling to pay for health care
- Economic hardship in general
- The need for help with insurance options when you reach age 65
- HIV-specific concerns
- The need for LGBT-friendly elder housing
- The need for targeted support groups and services
- The need for assistance with end-of-life planning
- The need for help navigating the health care system
- The need for hardware (computers, tablets), internet access, and technical assistance to isolated, low-income LGBT elders so that they can access virtual support groups and other services during COVID

Key findings from the 2016-2018 BRFSS data include the following statistically significant differences between LGBT people 50-75 and straight/cisgender people 50-75:

- LGBT elders reported higher rates of fair/poor overall health, and
- Were nearly twice as likely to report ever having been diagnosed with a depressive disorder,
- Were about as likely to be a veteran and to have children in the household, and were
- More likely to have four or more years of college education
- More likely to rent and less likely to own their home
- More likely to report difficulty paying for housing or food in past year
- More likely to report serious difficulty concentrating, remembering or making decisions
- More likely to fall and be injured in past year
- Reported four times the rate of suicidal thoughts in past year
- Reported three times the rate of lifetime sexual violence victimization

This is just one recent example of grassroots community research that is being conducted across the country and that could inform policy and services for our communities.

A lot of useful state SOGI data is regularly collected on public health surveys, but SOGI data collection needs to be standardized. The Centers for Disease Control and Prevention should require states to use the same SOGI questions and response options on the state BRFSS and Youth Risk Behavior Survey (YRBS) to allow for aggregation of data and analysis of experiences of relatively small, intersectional populations, such as Latina transgender women or Black lesbian and bisexual women. CDC should also move the SOGI questions to the core

survey, and no longer include them in an optional module. State BRFSS data, when combined, represent a much larger sample size (about 460,000) compared to many national surveys (National Health Interview Survey, n=87,000; National Survey on Drug Use and Health, n=70,000; National Health and Nutrition Examination Survey n=5,000).

Pooling multiple states' data and multiple years gives researchers a sufficiently large sample to look at subpopulations of LGBT people, including racial and ethnic groups, age cohorts, and other demographics. But this assumes that the SOGI questions are the same from state to state. CDC leadership is required to ensure that this is the case. This uniformity of practice can enhance the quality of the data.

Likewise, the CDC should require states to use consistent SOGI questions and response options, for the same reasons. Because of variation in questions and response options, some states collect SOGI data on their YRBS that CDC and researchers are unable to pool and include in their analyses.

3. Community-based research has indicated that LGBTQI+ people experience disparities in a broad range of areas. What factors or criteria should the Subcommittee on SOGI Data consider when reflecting on policy research priorities?

All publicly funded data systems—surveys, administrative data, and forms in clinical settings—should collect and use voluntary, private, and confidential SOGI data as a matter of course unless there is a compelling reason not to. De-identified, population-level data should be publicly reported so that public policy makers, service providers, health care providers, and others can target needed services and care to different populations. The federal government can play a leadership role with state and local governments, service providers, and health care providers to ensure that they collect and use these data to improve public health and wellbeing and quality of care and services.

The Subcommittee on SOGI Data should look at how it can work with federal administrators across agencies to add SOGI questions whenever possible to existing surveys and forms. It should ensure that large national data registries and research collaboratives—including the cardiovascular health and cancer registries, and the National COVID Cohort Collaborative N3C and COVID-NET—include SOGI. It should also work with NIH to ensure that SOGI questions are asked in clinical trials research. Life-saving COVID-19 vaccine and treatment clinical trials, conducted with \$900 million in U.S. government funding,³² were conducted without collecting SOGI data from participants—a major missed opportunity. In 2016 sexual and gender minority (SGM) people were designated as a health disparity population for research by the National Institutes of Health and the Agency for Healthcare Research and Quality.³³ It should now be the

³² Frank RG, Dach L, Lurie N. It was the government that produced COVID-19 vaccine success. *Health Affairs*. May 14, 2021. <https://www.healthaffairs.org/doi/10.1377/forefront.20210512.191448/>

³³ National Institute of Minority Health and Health Disparities. NIMHD Director's Message. Sexual and gender minorities formally designated as a health disparity population for research purposes. October 6, 2016. https://www.nimhd.nih.gov/about/directors-corner/messages/message_10-06-16.html

standard practice that SOGI data be collected in government-funded research, unless this doesn't make sense for a particular study.

Thank you for this opportunity to provide input into the Subcommittee on SOGI Data's important work. Should you have any questions, please contact Sean Cahill, Director of Health Policy Research, at scahill@fenwayhealth.org. Thank you.

Sincerely,

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