UCLA School of Law
Williams Institute

May 4, 2020

Secretary Alex Azar
Department of Health and Human Services
200 Independence Avenue SW
Washington, DC 20201

Dear Secretary Azur:

We are scholars at the Williams Institute, an academic research center at UCLA School of Law dedicated to conducting rigorous and independent research on sexual orientation and gender identity, including on disparities and discrimination facing lesbian, gay, bisexual, and transgender (LGBT) people. We collect and analyze original data as well as analyze governmental and private data. In addition, Williams Institute scholars have long worked with federal agencies to improve data collection on the U.S. population and have produced widely cited best practices for the collection of sexual orientation and gender identity information on population-based surveys.[1]

We are writing to the Department of Health and Human Services to address barriers to the collection, analysis, and regular public reporting of detailed disaggregated demographic data on individuals with COVID-19.

We appreciate that the CDC and other federal agencies are working to ensure accurate and robust data collection during this time. Such data assist the government in tracking testing, infection, hospitalization and other health-related outcomes for people who have been affected by COVID-19. However, we believe these data, and the efforts of the CDC and other entities, would be enhanced by the collection and timely reporting of data on patients' sexual orientation and gender identity, along with other demographic characteristics, including race, ethnicity, sex, primary language, disability status, and socioeconomic status. Such data would help the public health system respond to the crisis and would help policymakers address the needs of and distribute resources to those who are most vulnerable.

Research shows that many people in the LGBT community are particularly vulnerable to serious illness related to COVID-19 infection. For example, a recent report released by the Human Rights Campaign found that 21% of LGBQ adults have asthma compared to 14% of non-

[1] SEXUAL MINORITY ASSESSMENT RESEARCH TEAM (SMART), WILLIAMS INSTITUTE, BEST PRACTICES FOR ASKING QUESTIONS ABOUT SEXUAL ORIENTATION ON SURVEYS (2009), https://williamsinstitute.law.ucla.edu/wp-content/uploads/Best-Practices-SO-Surveys-Nov-2009.pdf; GENDER IDENTITY IN U.S. SURVEILLANCE (GENIUSS), WILLIAMS INSTITUTE, BEST PRACTICES FOR ASKING QUESTIONS TO IDENTIFY TRANSGENDER AND OTHER GENDER MINORITY RESPONDENTS ON POPULATION-BASED SURVEYS (2014), https://williamsinstitute.law.ucla.edu/wp-content/uploads/Survey-Measures-Trans-GenIUSS-Sep-2014.pdf.

LGBTQ adults and 37% of LGBTQ people smoke compared to 27% of non-LGBTQ people.[2] In addition, the analysis found that 1.4 million LGBTQ adults have diabetes, including one in five LGBTQ people over the age of 50.[3]

A recent Williams Institute report looking specifically at the transgender population found that 319,800 transgender adults in the U.S. have one or more medical conditions at put them at increased risk of serious illness related to COVID-19, including asthma (208,500), diabetes (81,100), heart disease (72,700), and HIV (74,800), and approximately 217,000 transgender adults in the U.S. are age 65 or older.[4] In addition, 137,600 transgender people lack health insurance and 450,000 have not gone to a doctor in the past year because they could not afford it.[5]

Other Williams Institute research has highlighted vulnerabilities among LGBT people in California. Among all LGBT adults in California, 361,000 are in fair or poor health overall, and many LGBT adults have underlying health conditions that put them at increased risk of serious illness related to COVID-19, such as asthma (216,000), diabetes (114,000), and heart disease (81,000).[6] A significant number of LGBT people in California are age 65 and older—an estimated 162,000 LGB and 9,000 transgender people—many of whom also suffer from asthma, heart disease, and diabetes.[7]

LGBT people are not the only subpopulation at elevated risk for infection and serious illness related to COVID-19. Data that are available indicate that communities of color have been disproportionately affected by the virus. For example, a recent report from the CDC found that among patients hospitalized with COVID-19 for whom data on race were collected, 33% were Black/African American compared to 18% in the community.[8] The report also found that death rates were substantially higher for Black/African American individuals (92.3 deaths per 100,000) and Hispanic/Latino individuals (74.3 deaths per 100,0000) than for White individuals (45.2 deaths per 100,000).[9]

Given what is known so far about increased risks and vulnerabilities facing certain subpopulations, we request that the Department update the COVID-19 surveillance systems to collect data on patients' race, ethnicity, sex, primary language, sexual orientation, gender identity, disability status, and socioeconomic status in line with federal standards, including

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[2] CHARLIE WHITTINGTON ET AL., HUMAN RIGHTS CAMPAIGN FOUNDATION, THE LIVES & LIVELIHOODS OF MANY IN THE LGBTQ COMMUNITY ARE AT-RISK AMIDST THE COVID-19 CRISIS 5 (2020), https://assets2.hrc.org/files/assets/resources/COVID19-IssueBrief-032020-FINAL.pdf?_ga=2.94294430.205881203.1588012193-590966580.1588012193.

[3] *Id.*

[4] Jody L. Herman & Kathryn O'Neill, Williams Institute, Vulnerabilities to COVID-19 among Transgender Adults in the U.S. 1 (2020), https://williamsinstitute.law.ucla.edu/wp-content/uploads/Trans-COVID19-Apr-2020.pdf.

[5] *Id.* at 2.

[6] Kathryn O'Neill, Williams Institute, Health Vulnerabilities to COVID-19 among LGBT Adults in California (forthcoming).

[7] ILAN H. MEYER & SOON KYU CHOI, WILLIAMS INSTITUTE, VULNERABILITIES TO COVID-19 AMONG OLDER LGBT ADULTS IN CALIFORNIA 1-2 (2020), https://williamsinstitute.law.ucla.edu/wp-content/uploads/Older-LGB-COVID-CA-Apr-2020.pdf.

[8] Shikha Garg et al., *Hospitalization Rates and Characteristics of Patients Hospitalized with Laboratory-Confirmed Coronavirus Disease 2019—COVID-NET, 14 States, March 1-30*, 69 MMWR 458 (2020).

[9] *Id.*

standards codified by Section 4302 of the Affordable Care Act.[10] We also support ensuring that the data are collected and reported using all appropriate privacy standards.

Sincerely,

Christy Mallory
State & Local Policy Director and Renberg Scholar of Law

Kerith J. Conron
Blachford Cooper Research Director and Distinguished Scholar

Brad Sears
David S. Sanders Distinguished Scholar and Associate Dean of Public Interest, UCLA Law

M.V. Lee Badgett
Williams Distinguished Scholar and Professor of Economics, University of Massachusetts Amherst

Ilan H. Meyer
Williams Distinguished Senior Scholar of Public Policy

Bianca D.M. Wilson
Senior Scholar of Public Policy

Jody L. Herman
Scholar of Public Policy

Soon Kyu Choi
Richard Taylor Public Policy Fellow

Luis Vasquez
Daniel H. Renberg Law Fellow

Kathryn O'Neill
Policy Analyst

The Williams Institute at UCLA School of Law

[10] U.S. DEP'T OF HEALTH AND HUM. SVCS., IMPLEMENTATION GUIDANCE ON DATA COLLECTION STANDARDS FOR RACE, ETHNICITY, SEX, PRIMARY LANGUAGE, AND DISABILITY STATUS (2011), https://aspe.hhs.gov/basic-report/hhs-implementation-guidance-data-collection-standards-race-ethnicity-sex-primary-language-and-disability-status.