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Data Collection on COVID-19: Public Comment

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Sheleen Dumas  
Department PRA Clearance Officer  
Office of the Chief Information Officer  
U.S. Department of Commerce  
Submitted via *regulations.gov*

RE: Agency Information Collection Activities; Submission to the Office of Management and Budget (OMB) for Review and Approval; Comment Request; Household Pulse Survey (OMB No. 0607-1013)

Dear Sheleen Dumas:

Thank you for the opportunity to comment on the Department of Commerce's proposed revisions related to the Household Pulse Survey. See 86 Fed. Reg. 7692 (Feb. 1, 2021). 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.<sup>1</sup>

We appreciate that the Department of Commerce and other federal agencies are working to ensure accurate and robust data collection related to COVID-19 during this time. Such data inform the government about a broad range of topics related to the pandemic. The Household Pulse Survey, for example, provides information about the health and economic wellbeing of American people, including their employment, income loss, food and housing security, mental health and access to health care, and educational outcomes.<sup>2</sup> Other federal COVID-19 data

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<sup>1</sup> 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>.

<sup>2</sup> 2020 COVID-19 Household Pulse Survey: Phase 3, US Census Bureau, Jan. 6, 2021, available at [https://www2.census.gov/programs-surveys/demo/technical-documentation/hhp/Phase3\\_Questionnaire\\_01\\_06\\_21\\_English.pdf](https://www2.census.gov/programs-surveys/demo/technical-documentation/hhp/Phase3_Questionnaire_01_06_21_English.pdf).

collection activities track testing, hospitalization, and other health related-outcomes for people who have been affected by COVID-19.<sup>3</sup>

The Household Pulse Survey and other data collection activities collect demographic data, including information about race, sex, and national origin, however, they do not include measures of sexual orientation and gender identity.<sup>4</sup> As a result, it is impossible to track the impact of the pandemic on LGBT people using federal data. We believe that data collected through the Household Pulse Survey and other COVID-19 monitoring systems would be enhanced by the collection and timely reporting of data on individuals' sexual orientation and gender identity. Such data would help the federal government, state governments, the public health system, service providers, and others respond to the crisis and equitably distribute resources to those who are most vulnerable.

Our comments address the importance and feasibility of including sexual orientation and gender identity measures on the Household Pulse Survey and other surveys conducted by the U.S. Department of Commerce that monitor the impacts of the COVID-19 pandemic. We recognize that sexual orientation and gender identity measures are not included in the current proposed revisions, but hope that the agency will consider adding these questions to the Household Pulse Survey through future revisions.

## **I. Health and Economic Disparities Facing LGBT People Prior to March 2020**

Recent research shows that LGBT people—particularly LGBT people of color—are particularly vulnerable to the health and economic impacts of the COVID-19 pandemic. However, most of this research is based on data collected prior to March 2020, and therefore does not provide a complete picture of how the pandemic has affected the lives of LGBT people.

This body of research shows that LGBT people were more likely than non-LGBT people to have underlying health conditions that would put them at increased risk of serious illness related to COVID-19 infection and were more likely to work in industries hardest hit by the pandemic. For example, a recent report published by the U.S. Centers for Disease Control and Prevention (CDC) found that LGB people were at higher risk for health conditions linked to serious COVID-19 illness including asthma, chronic obstructive pulmonary disease, stroke, kidney disease, cancer, and heart disease.<sup>5</sup> The article was based on data collected through the CDC's Behavioral Risk Factor Surveillance System between 2017 and 2019.<sup>6</sup> Recognizing the limitations in current data collection activities, the authors noted that “[c]urrent COVID-19 surveillance systems do not capture information about sexual orientation” and that collecting such data “would improve knowledge about disparities in infection and adverse outcomes by sexual orientation, thereby informing more equitable responses to the pandemic.”<sup>7</sup>

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<sup>3</sup> See, e.g., National Testing, US Dep't of Health and Hum. Svcs., <https://protect-public.hhs.gov/pages/national-testing> (last visited Feb. 21, 2021).

<sup>4</sup> *Id.*

<sup>5</sup> Kevin C. Heslin & Jeffrey E. Hall, *Sexual Orientation Disparities in Risk Factors for Adverse COVID-19-Related Outcomes, by Race/Ethnicity—Behavioral Risk Factor Surveillance System, United States, 2017-2019*, 70 MMWR 149 (2021), available at <https://www.cdc.gov/mmwr/volumes/70/wr/pdfs/mm7005a1-H.pdf>.

<sup>6</sup> *Id.*

<sup>7</sup> *Id.* At 149.

Recent studies by the Williams Institute and other organizations documented similar disparities facing LGBT people before the pandemic began. A 2020 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 that 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.<sup>8</sup> In addition, 137,600 transgender people lack health insurance and 450,000 had not gone to a doctor in the past year because they could not afford it.<sup>9</sup>

Williams Institute research also highlighted health vulnerabilities among LGBT people in California. Among all LGBT adults in California, 361,000 were in fair or poor health overall before the pandemic began, and many LGBT adults had 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).<sup>10</sup> 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.<sup>11</sup>

Other Williams Institute research found that many LGBT people experienced economic insecurity even before the pandemic began. For example, a report based on data collected in 2017 found that nearly 27% of LGBT people had experienced food insecurity in the prior year. Rates of prior year food insecurity were particularly high for LGBT women (31%) and Black LGBT (37%) and Latino/a LGBT (32%) people.<sup>12</sup> Another report based on data collected between 2016 and 2019 found that 8% of transgender people and 3% of cisgender LGB people experienced homelessness within the prior year compared to 1% of non-LGBT people.<sup>13</sup> Among LGB adults, Black respondents had significantly higher rates (6%) of recent housing instability.<sup>14</sup>

Additionally, a 2020 report released by the Human Rights Campaign found that 21% of LGBQ adults have asthma compared to 14% of non-LGBTQ adults and 37% of LGBTQ people smoke compared to 27% of non-LGBTQ people.<sup>15</sup> In addition, the analysis found that 1.4 million LGBTQ adults have diabetes, including one in five LGBTQ people over the age of 50.<sup>16</sup>

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<sup>8</sup> 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>.

<sup>9</sup> *Id.* at 2.

<sup>10</sup> Kathryn O’Neill, Williams Institute, Health Vulnerabilities to COVID-19 among LGBT Adults in California 1 (2020) <https://williamsinstitute.law.ucla.edu/publications/covid19-health-lgbt-ca/>.

<sup>11</sup> 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>.

<sup>12</sup> BIANCA D.M. WILSON & KERITH J. CONRON, WILLIAMS INSTITUTE, NAT’L ESTIMATES OF FOOD INSECURITY: LGBT PEOPLE AND COVID-19 1 (2020), <https://williamsinstitute.law.ucla.edu/wp-content/uploads/Food-Insecurity-COVID19-Apr-2020.pdf>.

<sup>13</sup> BIANCA D.M. WILSON ET AL., WILLIAMS INSTITUTE, HOMELESSNESS AMONG LGBT ADULTS IN THE US 1 (2020), <https://williamsinstitute.law.ucla.edu/wp-content/uploads/LGBT-Homelessness-May-2020.pdf>.

<sup>14</sup> *Id.*

<sup>15</sup> 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](https://assets2.hrc.org/files/assets/resources/COVID19-IssueBrief-032020-FINAL.pdf?_ga=2.94294430.205881203.1588012193.590966580.1588012193).

<sup>16</sup> *Id.*

The report also found that 40% of LGBTQ adults work in industries hardest hit by the pandemic, including restaurant and food services, health care, education, and retail.<sup>17</sup>

## **II. Inclusion of Sexual Orientation and Gender Identity Measures in COVID-19 Data Collection Activities and the Impact of COVID-19 on LGBT People**

A handful of state governments and private entities have begun to include measures of sexual orientation and gender identity in surveys and other data collection activities related to COVID-19. For example, in September 2020 the California Legislature passed a bill requiring health care providers to collect information about patients' sexual orientation and gender identity in order to track the health impacts of the pandemic on LGBT communities.<sup>18</sup> Pennsylvania announced similar plans to collect sexual orientation and gender identity data in its COVID-19 monitoring systems in May 2020.<sup>19</sup>

Some private entities have also incorporated measures of sexual orientation and gender identity into their surveys related to COVID-19. Reports based on data collected through these surveys indicate that the pandemic has more severely impacted LGBT people than non-LGBT people—particularly LGBT people of color.

In February 2021, the Williams Institute published a report based on data collected through the Ipsos-Axios survey between August and December 2020.<sup>20</sup> The report found that LGBT communities of color have disproportionately experienced the health and economic impacts of COVID-19. For example, among those tested, an estimated 15% of LGBT people of color have tested positive for COVID-19, compared to 7% of non-LGBT White people.<sup>21</sup> About one-third of LGBT people of color personally knew someone who died of COVID-19 compared to one-fifth of White LGBT and White non-LGBT people.<sup>22</sup> In addition, LGBT respondents were more likely than non-LGBT respondents to have been laid off (12% vs 8%) or furloughed from their jobs (14% vs 10%), report problems affording basic household goods (24% vs 12%), and report having problems paying their rent or mortgage (20% vs 12%).<sup>23</sup> These economic disparities were even greater when comparing LGBT people of color to non-LGBT White people: 29% of LGBT people of color reporting having less ability to pay for household goods and 26% percent reported being unable to pay their rent or mortgage compared to 14% and 9% of non-LGBT White respondents, respectively.<sup>24</sup>

In addition, a report published by the Movement Advancement Project based on data collected through the polling series by NPR, the Robert Wood Johnson Foundation, and the

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<sup>17</sup> *Id.* at 2.

<sup>18</sup> S.B. 392, 2019-2020 Gen. Assem. (Cal. 2020) (enacted).

<sup>19</sup> Press Release, Gov. Tom Wolf Announces Inclusion of Gender Identity, Sexual Orientation or Expression in COVID-19 Data Collection (May 13, 2020), <https://www.governor.pa.gov/newsroom/gov-wolf-announces-inclusion-of-gender-identity-sexual-orientation-or-expression-in-covid-19-data-collection/>.

<sup>20</sup> BRAD SEARS ET AL., WILLIAMS INSTITUTE, THE IMPACT OF THE FALL 2020 COVID-19 SURGE ON LGBT PEOPLE IN THE US 2 (2021), <https://williamsinstitute.law.ucla.edu/wp-content/uploads/COVID-LGBT-Fall-Surge-Feb-2102.pdf>.

<sup>21</sup> *Id.*

<sup>22</sup> *Id.* at 3

<sup>23</sup> *Id.*

<sup>24</sup> *Id.* at 4.

Harvard T.H. Chan School of Public Health documented similar outcomes for LGBT people.<sup>25</sup> The report found that nearly two-thirds (64%) of LGBTQ people and their families experienced a job loss or disruption since the pandemic began, compared to 45% of non-LGBTQ people.<sup>26</sup> Similar percentages of LGBTQ (66%) and non-LGBTQ people (44%) reported having at least one serious financial problem since the pandemic began.<sup>27</sup> Rates of financial insecurity were particularly high for LGBTQ people of color: Nearly all (95%) of Black LGBTQ households and 70% of Latino/a LGBTQ households reported having experienced at least one serious financial problem before the pandemic began.<sup>28</sup> LGBTQ people were also more likely than non-LGBTQ people to report recent food insecurity (19% vs 5%), loss of health insurance coverage (13% vs 6%), and disruptions to their children's education (52% vs 38%).<sup>29</sup>

Finally, the Human Rights Campaign published a survey based on data collected through polling conducted by PSB Research to study the impact of the pandemic on LGBTQ people.<sup>30</sup> The analysis found that many LGBTQ people have had their work hours reduced (30%), become unemployed (17%), and have had their pay cut (10%) since the pandemic.<sup>31</sup> Transgender people—particularly transgender people of color—had even higher rates of job insecurity. Nineteen percent of all transgender people and 26% of transgender people of color became unemployed compared to 12% of the general population.<sup>32</sup> Over half (54%) of all transgender people and 58% of transgender people of color had their work hours reduced compared to 23% of the general population.<sup>33</sup> And, 27% of all transgender people and 37% of transgender people of color had their pay cut compared to 7% of the general population.<sup>34</sup>

While these studies demonstrate that LGBT people have been disproportionately impacted by the COVID-19 pandemic, the data sources on which they were based are not as comprehensive as the Household Pulse Survey. In addition to questions about food and housing insecurity, and employment status, the Household Pulse Survey asks a range of questions about source of income, access to health insurance and medical care, COVID diagnosis and vaccine uptake, and impact on educational pursuits and access. Data collected by the U.S. Census Bureau on the Pulse Household Survey are likely to inform federal and state public health measures and recovery efforts.

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<sup>25</sup> MOVEMENT ADVANCEMENT PROJECT, THE DISPROPORTIONATE IMPACTS OF COVID-19 ON LGBTQ HOUSEHOLDS IN THE US: RESULTS FROM A JULY/AUGUST 2020 NATIONAL POLL (2021), <https://www.lgbtmap.org/file/2020-covid-lgbtq-households-report.pdf>.

<sup>26</sup> *Id.* at 1.

<sup>27</sup> *Id.* at 3.

<sup>28</sup> *Id.* at 5.

<sup>29</sup> *Id.* at 4.

<sup>30</sup> HUMAN RIGHTS CAMPAIGN & PSB RESEARCH, THE ECONOMIC IMPACT OF COVID-19 INTENSIFIES FOR TRANSGENDER AND LGBTQ COMMUNITIES OF COLOR (2021), [https://assets2.hrc.org/files/assets/resources/COVID19-EconImpact-Trans-POC-061520.pdf?\\_ga=2.95164383.293143299.1609796026-867693953.1600960438](https://assets2.hrc.org/files/assets/resources/COVID19-EconImpact-Trans-POC-061520.pdf?_ga=2.95164383.293143299.1609796026-867693953.1600960438).

<sup>31</sup> *Id.* at 2.

<sup>32</sup> *Id.*

<sup>33</sup> *Id.*

<sup>34</sup> *Id.*

### III. Conclusion

Given what is known so far about increased risks facing LGBT people, we request that the Department of Commerce update the Household Pulse Survey and other data collection activities related to COVID-19 to include measures of sexual orientation and gender identity. Including these measures would provide useful information about the impact of the pandemic on a subpopulation that is particularly vulnerable to the health and economic impacts of the COVID-19 pandemic.

Finally, we note our concern with potential harm to respondents of COVID-19 clinical data collection activities due to breach of confidentiality. We urge the Department of Commerce to ensure that the data are collected and reported using all appropriate privacy standards and to maintain confidentiality of respondents' medical and demographic information. Where confidentiality is breached, LGBT individuals ought to be protected from discrimination and in medical and other settings. We further note that there is no significant threat of harm associated with participation in the Household Pulse Survey.

Please do not hesitate to reach out for additional information. I can be reached at [mallory@law.ucla.edu](mailto:mallory@law.ucla.edu).

Sincerely,

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