July 23, 2025

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Director, Executive Secretariat
Health Resources and Services Administration
U.S. Department of Health and Human Services

RE: Agency Information Collection Activities: Submission to OMB for Review and Approval; Public Comment Request; Health Resources and Services Administration Uniform Data System

We appreciate the opportunity to provide comment on proposed changes to information collection through the Health Resources and Services Administration (HRSA) Uniform Data System (UDS), OMB No. 0915-0193—Revision. See 90 Fed. Reg. 26,592 (June 23, 2025). In particular, we write regarding the removal of "data elements related to sexual orientation and gender identity" in the UDS. Collecting, maintaining, and making such data publicly advances the agency's mission and purpose and its obligations under the law.

The undersigned are scholars affiliated with the Williams Institute at the UCLA School of Law. The Williams Institute, dedicated to conducting rigorous and independent research, collects and analyzes original data, as well as analyzes governmental and private data, and has long worked with federal agencies to improve data collection on the U.S. population. These efforts include producing widely cited best practices for the collection of sexual orientation and gender identity ("SOGI") information on population-based surveys.¹

Lesbian, gay, bisexual, and transgender (LGBT) people are a notable subgroup of the U.S. population and existing research based on federal data describes important differences in health and wellbeing related to sexual orientation and gender identity.² We offer this comment to

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federal-lgbt-data/.

¹ See, e.g., Gender Identity in U.S. Surveillance (GenIUSS) Group, Williams Inst., Best Practices for Asking Questions to Identify Transgender and Other Gender Minority Respondents on Population-Based Surveys (2014), https://williamsinstitute.law.ucla.edu/publications/geniuss-trans-pop-based-survey/; Sexual Minority Assessment Research Team (SMART), Williams Inst., Best Practices For Asking Questions About Sexual Orientation On Surveys (2009), https://williamsinstitute.law.ucla.edu/publications/smart-so-survey/

² E.g., Jody L. Herman & Kathryn K. O'Neill, Williams Inst., Well-Being Among Transgender People During the COVID-19 Pandemic (Nov. 2022), https://williamsinstitute.law.ucla.edu/wp-content/uploads/Trans-Pulse-Toplines-Nov-2022.pdf; Lauren J.A. Bouton, et al., Williams Inst., LGBT Adults Aged 50 and Older in the US During the COVID-19 Pandemic, https://williamsinstitute.law.ucla.edu/publications/older-lgbt-adults-us/; Ilan H. Meyer, Bianca D.M. Wilson & Kathryn O'Neill, Williams Inst., LGBTQ People in the US: Select Findings from the Generations and TransPop Studies (2021), https://williamsinstitute.law.ucla.edu/publications/generations-transpop-toplines/ (summarizing findings from LGBTQ-specific population-based national surveys, NIH-funded Generations (HD078526) and TransPop (HD090468) studies); see also Ilan H. Meyer & Lauren J. Bouton, Williamsinstitute.law.ucla.edu/publications/access-

underscore how data collection from federally qualified health centers ("FQHC") on sexual orientation and gender identity can improve insight into priorities outlined by the Department of Health and Human Services ("the Department") in the above-captioned Federal Register Notice.

I. <u>LGBT People are a Sizeable and Diverse Subgroup of the U.S. Population</u>

LGBT people make up a substantial portion of the U.S. population. Using data from the Behavioral Risk Factor Surveillance System Survey (BRFSS), a survey jointly administered by the U.S. Centers for Disease Control and Prevention and states, the Williams Institute estimates that:

- Approximately 5.5% of the U.S. adult population identifies as lesbian, gay, bisexual, or transgender.³ Applying these figures to the U.S. population, we estimate that over 14 million adults in the U.S. identify as LGBT.
- Approximately 1.3 million adults aged 18 and older identify as transgender.⁴
- In addition, based on data collected by Gallup, we estimate that approximately 1.2 million LGBT adults identify as nonbinary in the U.S.⁵

The LGBT population is remarkably diverse, and their experiences are not uniform but, rather, are shaped by factors such as race, ethnicity, socioeconomic status, geographical location, primary language, education, disability, religion, family composition, and age.⁶

II. SOGI Data Advance the Mission and Purposes of HHS, UDS, and the HRSA Health Center Program

The Department's notice impacts data collected by FQHCs about the populations they serve. Health centers, including FQHCs, are "community-based and patient-directed organizations that deliver affordable, accessible, quality, and cost-effective primary health care services to patients regardless of their ability to pay." Many FQHCs are located in medically underserved areas, such as rural communities, or provide care directed at underserved

³ Andrew R. Flores & Kerith J. Conron, Williams Inst., LGBT Adults in the U.S. Population (2023), https://williamsinstitute.law.ucla.edu/wp-content/uploads/LGBT-Adult-US-Pop-Dec-2023.pdf.

⁴ JODY L. HERMAN, ANDREW R. FLORES & KATHRYN K. O'NEILL, WILLIAMS INST., HOW MANY ADULTS AND YOUTH IDENTIFY AS TRANSGENDER IN THE UNITED STATES? (June 2022), https://williamsinstitute.law.ucla.edu/publications/trans-adults-united-states/.

⁵ Press Release, Williams Inst., *1.2 Million Adults in the U.S. Identify as Nonbinary* (June 21, 2021), https://williamsinstitute.law.ucla.edu/press/lgbtq-nonbinary-press-release/; *See also* BIANCA D.M. WILSON & ILAN MEYER, WILLIAMS INST., NONBINARY LGBTQ ADULTS IN THE U.S. (JUNE 2021),

https://williamsinstitute.law.ucla.edu/publications/nonbinary-lgbtq-adults-us/. This study used data sources from both cisgender and transgender LGBTQ community members.

⁶ INST. OF MED., *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding* (2011), http://www.iom.edu/Reports/2011/The-Health-of-Lesbian-Gay-Bisexual-and-Transgender-People.aspx.

⁷ 90 Fed. Reg. 26,592, 26,593 (June 23, 2025), https://www.govinfo.gov/content/pkg/FR-2025-06-23/pdf/2025-11444.pdf.

populations, such as those experiencing homelessness.⁸ FQHCs include organizations receiving grants under Section 330, community-based health care providers meeting requirements of the HRSA health center program but not receiving funding (referred to as "look-alikes"), and outpatient facilities operated by tribal or urban Indian organizations.⁹ Many FQHCs are federally funded—the Department provides grants to "approximately 15,500 [FQHCs] that provide primary health care to more than 31 million people."¹⁰

As part of their compliance with federal funding requirements, FQHCs are required to report standardized information about the performance and operation of health centers delivering health care services to underserved communities and vulnerable populations through the UDS. ¹¹ In its comment request, the Department described UDS data as aiding in the monitoring and evaluation of health centers receiving federal grants under Section 330 of the Public Health Service Act (PHSA) and similar grant programs. ¹² UDS data on patient characteristics and clinical conditions are used to "evaluate and improve health-center performance, ensure compliance with legislative mandates, and identify trends in health centers' impact on expanding access, addressing health disparities, improving quality, and reducing health care costs." ¹³

Data collection on the sexual orientation and gender identity of patients served by FQHCs is essential as it advances the mission and purposes of HHS, UDS, and the HRSA health center program. Ample research indicates that LGBT people experience unique barriers to accessing health care and face health disparities compared to non-LGBT people. Research also indicates that LGBT people are more likely to experience homelessness, poverty, and other types of economic insecurity compared to non-LGBT people. As a result, many LGBT people likely rely on FQHCs, some of which specifically provide health care tailored to LGBTQ populations and others of which serve underserved populations that disproportionately include LGBT people (such as people experiencing homelessness). ¹⁴ Therefore, the continued collection of SOGI data would assist the Department in fulfilling its stated goals on program evaluation and identifying trends in health care access and health disparities, particularly amongst medically underserved populations served by FQHCs.

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⁸ E.g., HEALTH RESOURCES & SERVICES ADMIN., Impact of the Health Center Program (April 2025), https://bphc.hrsa.gov/about-health-center-program/impact-health-center-program.

⁹ 42 U.S.C. § 1395x(aa)(4) (2024).

¹⁰ 90 Fed. Reg. at 26,593.

¹¹ See, e.g., CTR. FOR MEDICARE & MEDICAID SERV., UNIFORM DATA SYSTEM (UDS), https://www.cms.gov/files/document/sgm-clearinghouse-uds.pdf (last accessed July 10, 2025). ¹² 90 Fed. Reg. at 26,593.

¹³ CTR. FOR MEDICARE & MEDICAID SERV., UNIFORM DATA SYSTEM (UDS), https://www.cms.gov/files/document/sgm-clearinghouse-uds.pdf (last accessed July 10, 2025).

¹⁴ See Los Angeles LGBT Center, *Medical Services*, https://lalgbtcenter.org/services/medical-services/ (last accessed July 17, 2025); see also Tommy Royston, Healthcare Equity: Exploring How Two Community Health Centers That Specialize in LGBTQ Healthcare Frame Cultural Competence at 97-98 (May 2023) (Ph.D. dissertation, Univ. of San Diego), https://www.legalbluebook.com/bluebook/v22/rules/17-unpublished-and-forthcoming-sources/17-2-unpublished-materials?id=17726725&tokens=dissertation#b-17810325 (analyzing two FQHCs which both serve large populations of LGBTQ people, including one which had 62% LGBTQ patients in 2020).

a. LGBT People Experience Unique Barriers to Accessing Health Care

Ample evidence shows LGBT adults face barriers in accessing medical care.¹⁵ For example, one analysis using 2022 BRFSS data found that sexual minority women reported worse access to care across all measures when compared to heterosexual women, and LGB men and women were more likely to report not being able to afford medical care than their non-LGB counterparts.¹⁶ Research suggests that these disparities have persisted for years. An analysis of the 2013 National Health Interview Survey (NHIS) found that LGB adults were more likely to delay or not receive health care due to cost when compared to their heterosexual counterparts.¹⁷ Among transgender adults, the 2022 U.S. Transgender Survey found that 28% of respondents had not seen a healthcare provider in the year prior because of cost, and 43% of respondents did not receive any routine reproductive healthcare.¹⁸

A 2022 Williams Institute and UCLA Center for Health Policy Research study using data from the California Health Interview Study (CHIS) found important differences within the LGBT community as well, with bisexual men and women being the most likely of all groups to report not having a usual source of health care (27% and 24%, respectively) and one-third of transgender people in California reporting that they delayed or did not get needed healthcare. Additionally, data from the BRFSS showed that, compared to straight women, LBQ women were significantly less likely to have received screenings for reproductive-related cancers such as cervical and breast cancer. Amongst older adults, an analysis of 2021-2022 Census Household Pulse Survey data showed 15.7% of LGBT 50-64 year olds did not get needed care from a mental health professional in the past four weeks, compared to 8.2% of non-LGBT people in the same age bracket.

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¹⁵ NAT'L ACADS. OF SCIS., ENG'G, & MED., Chapter 12: Coverage, Access, and Utilization of Evidence-Based Health Care, in UNDERSTANDING THE WELL-BEING OF LGBTQI+ POPULATIONS 345 (2020), https://doi.org/10.17226/25877.

The Kevin H. Nguyen, et al., *Health Insurance Coverage and Access to Care by Sexual Orientation During the COVID-19 Pandemic: United States, January 2021–February 2022*, 114 Am. J. of Pub. Health 118, 122 (2023), <a href="https://ajph.aphapublications.org/doi/full/10.2105/AJPH.2023.307446?casa_token=KFgWLLU89UwAAAA:Fgva2Hdf8lxSeAvtu88snf_ECpOoF2BNmE21Sybk17d_OC_Y4-UsQEjb9abmrZFROkKUU5QibqqLa. See also Kevin H. Nguyen, et al., *Inequities in Self-Reported Social Risk Factors by Sexual Orientation and Gender Identity*, 5 JAMA HEALTH FORUM at e243176, https://jamanetwork.com/journals/jama-health-forum/fullarticle/2823975.

17 James M. Dahlhamer, et al., *Barriers to Health Care Among Adults Identifying as Sexual Minorities: *A US National Study*, 106 Am. J. of Public Health 1116 (2016), https://pmc.ncbi.nlm.nih.gov/articles/PMC4880242/.

18 ANKIT RASTOGI, ET AL., HEALTH AND WELLBEING: A REPORT OF THE 2022 U.S. TRANSGENDER SURVEY 1, 8, 27 (2025), https://transequality.org/sites/default/files/2025-06/USTS_2022Health%26WellbeingReport_WEB.pdf.

19 SUSAN H. BABEY, ET AL., UCLA CTR. FOR HEALTH POL'Y RESEARCH, GAPS IN HEALTH CARE ACCESS AND HEALTH INSURANCE AMONG LGBT POPULATIONS IN CALIFORNIA (2022), https://williamsinstitute.law.ucla.edu/wp-content/uploads/CA-Health-Care-Gaps-Feb-2022.pdf.

²⁰ BIANCA D.M. WILSON, ET AL., WILLIAMS INST., HEALTH AND SOCIOECONOMIC WELL BEING OF LBQ WOMEN IN THE US 1, 58 (March 2021), https://williamsinstitute.law.ucla.edu/publications/lbq-women-in-us/.

²¹ LAUREN J.A. BOUTON, AMANDA M. BRUSH & ILAN H. MEYER, WILLIAMS INST. *LGBT Adults Aged 50 and Older in the U.S. During the COVID-19 Pandemic* 1, 36 (Jan. 2023), https://williamsinstitute.law.ucla.edu/wp-content/uploads/LGBT-Older-Adults-Jan-2023.pdf.

Experiences of discrimination play a role in creating this disparity. Among respondents to the Williams Institute's national probability surveys conducted in 2016-2018, Generations and TransPop, almost 40% of sexual minority and 60% of transgender people reported worrying about being negatively judged in interactions with a health care provider. Another 2017 study based on a national probability survey found that 18% of LGBTQ people reported actually avoiding health care due to perceived discrimination. In addition, 8% of all LGBT respondents to a 2018 Center for American Progress study avoided or postponed needed medical care because of disrespect or discrimination from health care staff; that figure rose to 14% among those who had experienced discrimination on the basis of their SOGI in the past year. The reports of discrimination were not distributed equally among LGBT respondents, with 22% of transgender people surveyed reporting avoiding care within the past year because of SOGI-based discrimination. The 2022 USTS similarly found that 24% of transgender respondents did not see a healthcare provider in the year prior to the survey because they thought they would be disrespected or mistreated as a trans person. Pearly half (47%) of respondents to the same survey reported at least one negative interaction with a healthcare provider.

Access to health insurance is also a significant barrier to necessary health care. LGBT people have historically been uninsured at higher rates compared to non-LGBT people, although recent studies indicate this gap may be closing.²⁹ Research from the Williams Institute and others has consistently shown that LGBT adults are more likely than non-LGBT adults to rely on Medicaid for their health insurance.³⁰ Further, in states that have not adopted Medicaid

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²² J.D. Bosse et al., *Healthcare Mistreatment is Associated With Psychological Distress, Suicidality, and Substance Use Among Transgender and Nonbinary Emerging Adults*, 13 EMERGING ADULTHOOD 468 (2025), https://doi.org/10.1177/21676968241308316; Ilan H. Meyer, *Prejudice, Social Stress, and Mental Health in Lesbian, Gay, and Bisexual Populations*, 129 PSYCH. BULL. 674, 681–682 (2003), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2072932/.

²³ ILAN H. MEYER, ET AL., WILLIAMS INST., LGBTQ PEOPLE IN THE US:
SELECT FINDINGS FROM THE GENERATIONS AND TRANSPOP STUDIES 1, 27 (2021),
https://williamsinstitute.law.ucla.edu/wp-content/uploads/Generations-Transpop-Toplines-Jun-2021.pdf.

²⁴ Logan S. Casey et al., *Discrimination in the United States: Experiences of Lesbian, Gay, Bisexual, Transgender, and Queer Americans*, 54 HEALTH SERV. RES. 1454 (2019).

²⁵ Shabab Ahmed Mirza & Caitlin Rooney, *Discrimination Prevents LGBTQ People from Accessing Healthcare*, CTR. FOR AM. PROGRESS (Jan. 18, 2018), https://www.americanprogress.org/article/discrimination-prevents-lgbtqpeople-accessing-health-care/.

²⁶ *Id.*

²⁷ ANKIT RASTOGI, ET AL., HEALTH AND WELLBEING: A REPORT OF THE 2022 U.S. TRANSGENDER SURVEY at 29 (2025), https://transequality.org/sites/default/files/2025-06/USTS_2022Health%26WellbeingReport_WEB.pdf. ²⁸ Id. at 30.

²⁹ Gary J. Gates, *In U.S., LGBT More Likely Than Non-LGBT to Be Uninsured*, Gallup (Aug. 26, 2014), https://news.gallup.com/poll/175445/lgbt-likely-non-lgbt-uninsured.aspx; ARIELLE BOSWORTH, ET AL., HHS OFF. OF HEALTH POL'Y HEALTH INSURANCE COVERAGE AND ACCESS TO CARE FOR LGBTQ+ INDIVIDUALS: CURRENT TRENDS AND KEY CHALLENGES (2021), https://aspe.hhs.gov/sites/default/files/2021-07/lgbt-health-ib.pdf; LINDSEY DAWSON, ET AL., KAISER FAMILY FOUND., LGBTQ+ HEALTH POLICY (Sept. 30, 2024), https://www.kff.org/health-policy/?entry=table-of-contents-introduction.

³⁰ Brad Sears, et al., Williams Inst., LGBT Adults With Medicaid as Their Primary Source of Health Insurance 1, 2 (May 2025), https://williamsinstitute.law.ucla.edu/wp-content/uploads/Medicaid-LGBT-May-

expansion, nearly one-fifth of LGBT adults are uninsured.³¹ The Williams Institute analysis of CHIS data found that 37% of transgender people relied on Medicaid for their health insurance, compared to 21% of cisgender adults in California.³²

UDS data has been used to develop tools to address these disparities. One study found that increased SOGI data collection in FQHCs alongside a quality improvement initiative resulted in increased screening for syphilis (86.5 % increase), chlamydia and gonorrhea (109.0% increase), and HIV (132.4% increase) amongst LGBT patients.³³ Overall, collection of UDS data by FQHCs assists in understanding the extent of these disparities in health care access and their impact on LGBT adults. Thus, the continued collection of SOGI information would assist the Department in meeting its goal of understanding health centers' impact on "expanding access, addressing health disparities, improving quality, and reducing health care cost" for a vulnerable population.

b. There are Substantial Differences in Health Outcomes According to Sexual Orientation and Gender Identity

Research shows that LGBT people experience physical and mental health disparities compared to non-LGBT people,³⁴ which the minority stress model suggests could be connected to or exacerbated by anti-LGBT discrimination. Disparities are especially pronounced among LBQ women, gender minority individuals, older LGBT adults, and LGBT people of color. Furthermore, many significant health disparities exist between LGBT adults and their non-LGBT counterparts in the specific areas of medicine that Section 330 of the PHSA seeks to address through its grantmaking, including family medicine, internal medicine, obstetrics, gynecology, preventative health services, and diagnostic laboratory or radiology services.³⁵

Generally, many LGBTQ people report poor physical health. Data from the Williams Institute's Generations and TransPop studies showed that one in five (20.8%) LGBTQ people

<u>2025.pdf</u>; NAT'L ACADS. OF SCIS., ENG'G, & MED., Chapter 12: Coverage, Access, and Utilization of Evidence-Based Health Care, in UNDERSTANDING THE WELL-BEING OF LGBTQI+ POPULATIONS 345 (2020), https://doi.org/10.17226/25877.

³¹ Brad Sears, et al., Williams Inst., LGBT Adults With Medicaid as Their Primary Source of Health Insurance at 3 (May 2025), https://williamsinstitute.law.ucla.edu/wp-content/uploads/Medicaid-LGBT-May-2025.pdf.

³² SUSAN H. BABEY, ET AL., UCLA CTR. FOR HEALTH POL'Y RESEARCH, GAPS IN HEALTH CARE ACCESS AND HEALTH INSURANCE AMONG LGBT POPULATIONS IN CALIFORNIA at 5 (2022), https://williamsinstitute.law.ucla.edu/wp-content/uploads/CA-Health-Care-Gaps-Feb-2022.pdf.

³³ Bruce W. Furness, et al., *Transforming Primary Care for Lesbian, Gay, Bisexual, and Transgender People: A Collaborative Quality Improvement Initiative*, 18 Annals of Family Med. 292 (2020).

³⁴ NAT'L ACADS. OF SCIS., ENG'G, & MED., Chapter 12: Coverage, Access, and Utilization of Evidence-Based Health Care, in UNDERSTANDING THE WELL-BEING OF LGBTQI+ POPULATIONS 345 (2020), https://doi.org/10.17226/25877.

³⁵ 42 U.S.C. § 254b(b) (2024).

reported that their general health was fair or poor.³⁶ Subpopulations of LGBTQ people who are likely to experience marginalization based on multiple characteristics are more likely than other populations to report fair or poor health. In the same studies, LBO women (24.0%) and transgender people (25.9%) were more likely to report fair or poor general health than GBQ men (13.9%).³⁷ In addition, using 2012-2017 Gallup data, our study of differences across LGBT people by race found that more than a quarter (27%) of LGBT adults of color reported that their overall health was fair or poor, compared to 22% of white LGBT adults.³⁸ Research also shows that a substantial percentage of LGBT people experience serious health conditions, including life-threatening conditions.³⁹ Our Generations and TransPop studies found that among LGBTQ people, 18.0% had asthma, 16.3% had high blood pressure, 10.2% had diabetes, 6.0% had heart disease, and 3.0% had cancer. 40 The Williams Institute's study on LBO women analyzed BRFSS data and found that this sub-population has a significantly higher likelihood (10.8%) of being diagnosed with any cancer other than skin cancer compared to straight women (8.2%), straight men (6.3%), and GBQ cisgender men (7.4%).⁴¹ A Williams Institute literature review on the health of older LGBT adults found that cisgender LGB older adults had higher rates of disability, disease, and physical limitations than heterosexual counterparts, and older transgender people had a higher risk for poor physical health, disability, and depressive symptoms.⁴²

Research has observed disparities between LGBT and non-LGBT people in mental health outcomes as well. A report using 2023 Youth Risk Behavior Survey (YRBS) data found that, of transgender students, 72% felt persistent feelings of sadness or hopelessness and 26% attempted suicide in the past year. In the Williams Institute's study on differences across LGBT people by race, LGBT adults of all races were more likely to have been diagnosed with depression than

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SELECT FINDINGS FROM THE GENERATIONS AND TRANSPOP STUDIES at 29 (2021),

³⁶ ILAN H. MEYER, ET AL., WILLIAMS INST., LGBTQ PEOPLE IN THE US: SELECT FINDINGS FROM THE GENERATIONS AND TRANSPOP STUDIES 1, 30 (2021), https://williamsinstitute.law.ucla.edu/wp-content/uploads/Generations-TransPop-Toplines-Jun-2021.pdf.
³⁷ Id.

³⁸ BIANCA D.M. WILSON, ET AL., WILLIAMS INST., RACIAL DIFFERENCES AMONG LGBT ADULTS IN THE US: LGBT ADULTS AT THE INTERSECTION OF RACE 1 (2022), https://williamsinstitute.law.ucla.edu/wp-content/uploads/LGBT-Race-Comparison-Jan-2022.pdf.

³⁹ KATHRYN O'NEILL, WILLIAMS INST., HEALTH VULNERABILITIES TO COVID-19 AMONG LGBT ADULTS IN CALIFORNIA 8 (2020), https://williamsinstitute.law.ucla.edu/wp-content/uploads/LGBT-COVID-CA-Health-May-2020.pdf; ILAN H. MEYER & SOON KYU CHOI, WILLIAMS INST., 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.

⁴⁰ ILAN H. MEYER, ET AL., WILLIAMS INST., LGBTQ PEOPLE IN THE US:

https://williamsinstitute.law.ucla.edu/wp-content/uploads/Generations-TransPop-Toplines-Jun-2021.pdf

⁴¹ BIANCA D.M. WILSON, ET AL., WILLIAMS INST., HEALTH AND SOCIOECONOMIC WELL BEING OF LBQ WOMEN IN THE US 1, 50 (March 2021), https://williamsinstitute.law.ucla.edu/publications/lbq-women-in-us/.

⁴² SOON KYU CHOI & ILAN MEYER, WILLIAMS INST., LGBT AGING at 1 (Aug. 2016), https://williamsinstitute.law.ucla.edu/publications/lgbt-aging/.

⁴³ Nicolas A. Suarez, et al., Disparities in School Connectedness, Unstable Housing, Experiences of Violence, Mental Health, and Suicidal Thoughts and Behaviors Among Transgender and Cisgender High School Students — Youth Risk Behavior Survey, United States, 2023, 73 MORBIDITY & MORTALITY WEEKLY REPORT 50 (2024), https://www.cdc.gov/mmwr/volumes/73/su/su7304a6.htm?s cid=su7304a6 w.

their non-LGBT counterparts.⁴⁴ Analyses of our Generations and TransPop studies also found that three-quarters (76%) of LGBTQ people reported suicidal ideation over the course of their lives, with nearly one-third (30%) having made a suicide attempt.⁴⁵ Additionally, three-quarters of LGBTQ people also reported experiencing moderate psychological distress or serious mental illness in the prior month, with 28.2% reporting serious mental illness.⁴⁶

As demonstrated, existing research has illuminated differences in health outcomes by sexual orientation or gender identity. Thus, the continued collection of SOGI data in the UDS would provide for greater understanding about these health disparities, a clearly stated goal of the UDS to effectuate the purpose of the authorizing statutes.

c. <u>LGBT People Are Served By Existing FQHCs and Likely Constitute</u> <u>Significant Portions of the Underserved Populations Identified by Statute</u>

While UDS reporting is required of many health centers that serve a range of patients, health centers receiving grants under Section 330 of the PHSA primarily provide healthcare to a medically underserved population, meaning a population of an urban or rural area or a group of people designated by the Secretary of Health and Human Services as having a shortage of health services. Tertain population groups are also statutorily defined to be a "special medically underserved population." While LGBT people are not identified as a special medically underserved population by statute, the National Association of Community Health Centers acknowledges that health centers provide "comprehensive, culturally competent primary health services to a wide range of vulnerable populations such as... the LGBTQ+community."

⁴⁴ Soon Kyu Choi, et al., Williams Inst., Black LGBT Adults in the US 21 (2021),

https://williamsinstitute.law.ucla.edu/publications/black-lgbt-adults-in-the-us/; BIANCA D.M. WILSON, ET AL., WILLIAMS INST., WHITE LGBT ADULTS IN THE US 20 (2022), https://williamsinstitute.law.ucla.edu/wp-content/uploads/LGBT-White-SES-Jan-2022.pdf; BIANCA D.M. WILSON ET AL., WILLIAMS INST., AMERICAN INDIAN AND ALASKAN NATIVE LGBT ADULTS IN THE US 24 (2021), https://williamsinstitute.law.ucla.edu/WP-CONTENT/UPLOADS/LGBT-AIAN-SES-OCT-2021.PDF; BIANCA D.M. WILSON ET AL., WILLIAMS INST., AAPI LGBT ADULTS IN THE US 24 (2021), https://williamsinstitute.law.ucla.edu/wp-content/uploads/LGBT-AAPI-SES-May-2021.pdf.

⁴⁵ ILAN H. MEYER, ET AL., WILLIAMS INST., LGBTQ PEOPLE IN THE US: SELECT FINDINGS FROM THE GENERATIONS AND TRANSPOP STUDIES at 32 (2021),

 $[\]underline{\text{https://williamsinstitute.law.ucla.edu/wp-content/uploads/Generations-TransPop-Toplines-Jun-2021.pdf}^{46}\ Id$

⁴⁷ 42 U.S.C. § 254b(a)(3) (2024).

⁴⁸ 42 U.S.C. § 254b(a)(1) (2024).

⁴⁹ NAT'L ASSOC. OF COMM. HEALTH CTRS., *Special Populations*, https://www.nachc.org/resource-collection/special-populations/ (last accessed July 10, 2025).

Some existing FQHCs specialize in care for LGBT people and serve mostly LGBT patients.⁵⁰ Additionally, LGBT people likely constitute significant portions of the populations identified in Section 330 of the PHSA as "special medically underserved populations," which are people experiencing homelessness, residents of federal housing, and migratory or seasonal agricultural workers.⁵¹ Research shows that LGBT people disproportionately experience homelessness. For example, a 2020 Williams Institute report using Generations and TransPop data found that sexual minority adults were twice as likely as the general population to have experienced homelessness in their lifetime.⁵² The same report found that 8.3% of transgender people, versus 1.4% of cisgender straight individuals, experienced homelessness in the prior year.⁵³

Residents of federal housing and seasonal or migratory agricultural workers are also statutorily defined to be special underserved populations. A Center for American Progress survey found that LGBTQ respondents, particularly transgender and disabled LGBTQ respondents, relied on public housing assistance at a significantly higher rate compared to non-LGBTQ respondents.⁵⁴ While reliable data are lacking on LGBTQ seasonal or agricultural workers, research is available on the adult immigrant LGBT population in the U.S. As only one third (32%) of crop farmworkers in the U.S. were U.S. born, these data may help in understanding this subpopulation.⁵⁵ Williams Institute research using both private and federal data sets showed that over 3% of all immigrant adults in the U.S., or nearly 1.3 million people, identify as LGBT.⁵⁶ Of this group, 289,700 are undocumented.⁵⁷

The continued collection of SOGI data by health centers serving the LGBTQ population primarily or as an important subset of another population may be particularly useful to inform public health interventions for medically underserved populations, furthering the Department's stated goals in its information collection practices.

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⁵⁰ Los Angeles LGBT Center, *Medical Services*, https://lalgbtcenter.org/services/medical-services/ (last accessed July 17, 2025).

⁵¹ 42 U.S.C. § 254b (2024).

⁵² BIANCA D.M. WILSON, ET AL., WILLIAMS INST., HOMELESSNESS AMONG LGBT ADULTS IN THE US (May 2020), https://williamsinstitute.law.ucla.edu/publications/lgbt-homelessness-us/.

⁵³ Id.

⁵⁴ Caitlin Rooney, et al., CTR. FOR AM. PROGRESS, *Protecting Basic Living Standards for LGBTQ People* (Aug. 13, 2018), https://www.americanprogress.org/article/protecting-basic-living-standards-lgbtq-people/.

⁵⁵ U.S. DEP'T OF AGRICULTURE, ECON. RESEARCH SERV., *Farm Labor* (July 7, 2025), https://www.ers.usda.gov/topics/farm-economy/farm-labor.

⁵⁶ SHOSHANA K. GOLDBERG & KERITH J. CONRON, WILLIAMS INST., LGBT ADULT IMMIGRANTS IN THE UNITED STATES 1, 2, 19 (Feb. 2021), https://williamsinstitute.law.ucla.edu/publications/lgbt-immigrants-in-the-us/.

⁵⁷ Id. at 2.

III. Evidence Supports Continued Inclusion of SOGI Measures in the UDS and Other Federal Surveys

There is a strong evidence base demonstrating the importance of including sexual orientation and gender identity measures in federal data collections, including in administrative and clinical settings, along with outlining best practices for their implementation. So SOGI measures have been implemented and evaluated on community surveys, privately funded surveys, and some government-funded population surveys for decades. In March 2022, after convening a panel of experts, the National Academies of Sciences, Engineering and Medicine released a consensus report documenting the results of a rigorous evaluation of sex, gender identity, and sexual orientation measures, identifying best practices for their use and integration ("NASEM Report"). Notably, the study advocates for the adoption of measures that allow self-identification of gender in all contexts, including in administrative forms and health records. The NASEM Report is considered the gold standard model for agencies when designing data collection inclusive of SOGI.

In the context of health centers, a 2011 Institute of Medicine report recommended that SOGI data be collected for all patients accessing clinical care.⁶³ Subsequently, when the UDS began collecting sexual orientation and gender identity data in 2016,⁶⁴ this became the first federal requirement to collect SOGI data in any U.S. healthcare setting.⁶⁵ Studies have found that this requirement led to increased compliance over time, with FQHCs collecting SOGI data for about three quarters of all patients as of 2021.⁶⁶

FEDERAL EVIDENCE AGENDA ON LGBTQI+ EQUITY (2023), https://www.whitehouse.gov/wp-content/uploads/2023/01/Federal-Evidence-Agenda-on-LGBTQI-Equity.pdf.

⁵⁸ Off. of Disease Prevention & Health Promotion, *Lesbian, Gay, Bisexual, and Transgender Health*, Healthy People 2030, https://health.gov/healthypeople/objectives-and-data/browse-objectives/lgbt (last visited July 14, 2025).

⁵⁹ ILAN H. MEYER & LAUREN J.A. BOUTON, WILLIAMS INST., *Impact of Executive Orders on Access to Federal Data* (2025), https://williamsinstitute.law.ucla.edu/wp-content/uploads/SOGI-Data-Removal-EO-Feb-2025.pdf.

⁶⁰ MEASURING SEX, GENDER IDENTITY, AND SEXUAL ORIENTATION FOR THE NATIONAL INSTITUTES OF HEALTH, NAT'L ACADEMIES OF SCIENCES, ENGINEERING, & MED. (2022), https://www.nationalacademies.org/ourwork/measuring-sex-gender-identity-and-sexual-orientation-for-the-national-institutes-of-health.

⁶¹ See Id., at 8-10, 37, and 103-138. See also Kellan E. Baker, et al., Advancing Sexual and Gender Minority Population Health Using Electronic Health Record Data, 113 Am. J. of Pub. Health 1287 (2023), https://ajph.aphapublications.org/doi/abs/10.2105/AJPH.2023.307467?journalCode=ajph.

⁶² OFF. MGMT. & BUDGET, RECOMMENDATIONS ON THE BEST PRACTICES FOR THE COLLECTION OF SEXUAL ORIENTATION AND GENDER IDENTITY DATA ON FEDERAL STATISTICAL SURVEYS (2023), https://www.whitehouse.gov/wp-content/uploads/2023/01/SOGI-Best-Practices.pdf.; OFF. Sci. & Tech. Policy,

⁶³ Institute of Medicine Committee on Lesbian, Gay, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities, The Health of Lesbian, Bisexual, and Transgender People (2011), https://www.ncbi.nlm.nih.gov/books/NBK64806/.

⁶⁴ CTR. FOR MEDICARE & MEDICAID SERV., UNIFORM DATA SYSTEM (UDS), https://www.cms.gov/files/document/sgm-clearinghouse-uds.pdf (last accessed July 10, 2025).

⁶⁵ Alex McDowell, et al., *Sexual Orientation and Gender Identity Data Reporting Among U.S. Health Centers*, 62 Am. J. of Preventative Medicine at E325 (2022), https://www.ajpmonline.org/article/S0749-3797(22)00056-3/abstract.

⁶⁶ See e.g., Michael Liu, et al., Sexual Orientation and Gender Identity Data Completeness at US Federally

We also write to emphasize the importance of protection against discrimination related to data collection. HRSA has begun implementing a new system to modernize UDS data reporting, referred to as UDS+, which is meant to aid health centers in submitting de-identified patient data. ⁶⁷ This modernization initiative underscores the importance of both privacy protections in patient data and the ability of health centers to report sensitive patient data. We note our concern about potential harm to LGBTQ+ health center patients should there be a breach of confidentiality. All entities responsible for data collection must ensure the confidentiality of respondents' demographic information under all appropriate privacy standards to reduce the potential harm to respondents.

In sum, decades of research on the inclusion of SOGI measures in federal data collections, and research specifically focused on SOGI data collection by FQHCs, indicate that these data provide important and useful information, do not compromise data collection generally, and are not difficult or burdensome for FQHCs to collect.

IV. Conclusion

The Department proposes to eliminate the requirement that health centers collect SOGI data in upcoming iterations of UDS. Existing evidence suggests that these data illuminate existing disparities in healthcare access and health outcomes for LGBT people. Insight into these differences, through the continued inclusion of SOGI measures, could improve the ability of lawmakers, researchers, and the general public to better understand and address the wellbeing of the American population through the Public Health Services Act and other laws, policies, and health interventions.

The Williams Institute appreciates the opportunity to submit this comment as the Department considers its plans for upcoming UDS collections. Please contact us if you would like to discuss our submission or have any questions.

Respectfully Submitted,

Qualified Health Centers, 2020 and 2021, 113 Am. J. of Public Health 883, 883-892 (2023), https://ajph.aphapublications.org/doi/epub/10.2105/AJPH.2023.307323 (finding that FQHCs had SO data for 75% of patients and GI data for 70% in 2020-21); Alex McDowell, et al., Sexual Orientation and Gender Identity Data Reporting Among U.S. Health Centers, 62 Am. J. of Preventative Med. E325 (2022),

https://www.ajpmonline.org/article/S0749-3797(22)00056-3/abstract (finding that health centers had SOGI data for 75% of patients in 2019); Chris Grasso, et al., *Using sexual orientation and gender identity data in electronic health records to assess for disparities in preventive health screening services*, 142 INT'L J. OF MED. INFORMATICS 104245 (2020), https://doi.org/10.1016/j.ijmedinf.2020.104245.

⁶⁷ E.g., Health Resources & Services Admin., Uniform Data System (UDS) Test Cooperative (2025), https://web.archive.org/web/20250308202001/https://bphc.hrsa.gov/data-reporting/uds-training-and-technical-assistance/uniform-data-system-uds-test-cooperative.

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