NSTC Subcommittee on Equitable Data Office of Science and Technology Policy Eisenhower Executive Office Building 1650 Pennsylvania Ave. NW Washington, DC 20504 Submitted via *email* to equitabledata@ostp.eop.gov

RE: Request for Information; Federal Evidence Agenda on LGBTQI+ Equity (RIN 2022-18219)

To Whom It May Concern,

We are grateful for the opportunity to provide comments to the White House Office of Science and Technology Policy ("OSTP") on its above-captioned request for information, which seeks to help inform the development of the Federal Evidence Agenda on LGBTQI+ Equity (the "Equity Agenda"). *See* 87 Fed. Reg. 52,083 (August 24, 2022).

The undersigned are scholars affiliated with the Williams Institute at the UCLA School of Law. We are dedicated to conducting rigorous and independent research on sexual orientation and gender identity ("SOGI"), including on the demographics of lesbian, gay, bisexual, and transgender ("LGBT") people. We collect and analyze original data, as well as analyzes governmental and private data, and has long worked with federal agencies to improve SOGI data collection among the U.S. population.

Our efforts include producing widely cited best practices for the collection of SOGI information on population-based surveys. These reports are important resources for reviews of what was known about SOGI measurement at the time they were published, with research and practice progressing in this field in the time since and including our continuing contributions. For example, one of the undersigned, Bianca D.M. Wilson, was a member of an ad hoc panel convened by the National Academies of Sciences, Engineering, and Medicine to focus on SOGI-related methodological issues (the "NASEM Panel"). This past March, the NASEM Panel released its consensus study report offering guidance and best practices for collecting data on SOGI, as well as on variations in sex characteristics, in population-based surveys, and also in clinical and administrative settings. In this comment, we provide technical guidance and information in response to the specific questions posed in the RFI.

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/wp-content/uploads/Survey-Measures-Trans-GenIUSS-Sep-2014.pdf; Sexual Minority Assessment Research Team (SMART), Williams Inst., 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.

² NAT'L ACADEMIES OF SCIENCES, ENGINEERING, & MED., MEASURING SEX, GENDER IDENTITY, AND SEXUAL ORIENTATION (2022), https://nap.nationalacademies.org/catalog/26424/measuring-sex-gender-identity-and-sexual-orientation.

³ *Id*.

I. Describing Disparities

(1) Describe disparities faced by LGBTQI+ individuals that could be better understood through Federal statistics and data collection.

Experience indicates that when SOGI measures are included in surveys and other information-gathering systems, inequities are observed. Existing data show a host of negative outcomes for LGBT versus non-LGBT people related to social, economic, physical, and psychological wellbeing.⁴

Williams Institute research, based on both private and government datasets, shows higher rates of economic insecurity among LGBT populations. For example, Williams Institute research has documented that poverty rates are higher for LGBT than non-LGBT people, on average, and are particularly high for bisexual, transgender, and adults of color. We have also found that LGBT people are more likely to experience food insufficiency and housing instability than their non-LGBT peers. This research is consistent with research by other experts, including federal agencies, documenting similar disparities.

Decades of research have also documented health disparities facing LGBT people. Three reports⁸ by the National Academies of Sciences,⁹ Engineering, and Medicine¹⁰ and three sets of Healthy People Objectives over the last 20 years have summarized evidence of significant and broad-sweeping health disparities experienced by LGBT people, despite the omission of SOGI measures from many data sources and federal health surveys.¹¹ More specifically, health disparities have been observed across the life course and in every domain of health including

⁴ See, e.g., 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/wp-content/uploads/Generations-TransPop-Toplines-Jun-2021.pdf (summarizing findings from our LGBTQ-specific population-based national surveys through the NIH-funded Generations (HD078526) and TransPop (HD090468) studies on sexual and gender minority people, respectively).

⁵ M.V. LEE BADGETT, SOON KYU CHOI & BIANCA D.M. WILSON, WILLIAMS INST., LGBT POVERTY IN THE UNITED STATES: A STUDY OF DIFFERENCES BETWEEN SEXUAL ORIENTATION AND GENDER IDENTITY GROUPS 14–15 (2019), https://williamsinstitute.law.ucla.edu/wp-content/uploads/National-LGBT-Poverty-Oct-2019.pdf (finding that poverty rates were higher for LGBT people when compared to non-LGBT people across every age group, with observed differences being statistically significant among people aged 18 to 44 years old).

⁶ KERITH J. CONRON ET AL., WILLIAMS INST., FOOD INSUFFICIENCY AMONG LGBT ADULTS DURING THE COVID-19 PANDEMIC (2022), https://williamsinstitute.law.ucla.edu/wp-content/uploads/LGBT-Food-Insufficiency-Apr-2022.pdf.

⁷ ADAM P. ROMERO, SHOSHANA K. GOLDBERG & LUIS A. VASQUEZ, WILLIAMS INST., LGBT PEOPLE AND HOUSING AFFORDABILITY, DISCRIMINATION, AND HOMELESSNESS (2020), https://williamsinstitute.law.ucla.edu/wp-content/uploads/LGBT-Housing-Apr-2020.pdf.

⁸ Inst. of Med., The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding (2011).

⁹ NAT'L ACADEMIES OF SCIENCES, ENGINEERING, & MED, UNDERSTANDING THE WELL-BEING OF LGBTQI+ POPULATIONS (2000).

¹⁰ Inst. of Med., Lesbian Health: Current Assessment and Directions for the Future (1999).

¹¹ Office of Disease Prev. & Health Promo., *Healthy People 2030: Increase the Number of National Surveys that Collect Data on Transgender Populations*, U.S. DEP'T OF HEALTH & HUM. SVCS., health.gov/healthypeople/objectives-and-data/browse-objectives/lgbt/increase-number-national-surveys-collect-data-transgender-populations-lgbt-02 (last visited Sept. 24, 2022).

access to health services, adolescent health, cancer, health-related quality of life and well-being, HIV, immunization and infectious diseases, injury and violence prevention, mental health, nutrition and weight status, sexually transmitted diseases, social determinants of health, substance abuse, and tobacco use.

Furthermore, LGBT people are more likely to report concerns with safety, violence, and the criminal justice system. For example, a recent analysis of National Crime Victimization Survey data conducted by the Williams Institute indicated that LGBT people report experiences of violence perpetrated by strangers, on average, at similar rates as non-LGBT people, and higher rates of violence at the hands of well-known offenders. Research conducted by the Williams Institute also found that LGB-identified people are three times more likely to be incarcerated than the general U.S. population; among women, particularly Black and Latina women. Black and Latina women.

Although inequities in all of these areas are well-documented, continued and expanded SOGI data collection is necessary continue to assess inequities facing LGBT people, to identify and respond to the causes of these inequities, to understand the impact of policies and other interventions on these outcomes, and to assess the presence of other inequities for which data are presently lacking. Accordingly, the Equity Agenda should direct federal agencies to expand SOGI data collection on all federal surveys that produce information about social, economic, physical, and psychological well-being.

Additionally, due to data limitations, the needs of some populations remain largely unknown. For example, no federal surveys currently collect information on intersex people, or variations in sex characteristics, and as a result, little to no population-level data is available regarding these community members. Intersex people, or people with differences in sex development, are individuals who are born with or develop differences in the development of sex traits, including sex chromosomes, hormones, internal anatomy, and/or gonads. Many intersex people were subjected as children to non-consensual, non-emergency medical procedures for the purposes of gender assignment and/or "normalization." Such interventions appear to be associated with negative consequences later in life, such as decreased general well-being and rates of school completion. Evidence from non-governmental sources indicates that intersex people experience higher levels of depression than non-intersex people. The Equity Agenda should direct federal agencies to conduct research on best practices to gather data about intersex

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¹² Andrew R. Flores et al., *Victimization Rates and Traits of Sexual and Gender Minorities in the United States: Results from the National Crime Victimization Survey, 2017*, 6 SCI. ADV. eaba6910 (2020).

¹³ Ilan H. Meyer et al., *Incarceration Rates and Traits of Sexual Minorities in the United States: National Inmate Survey, 2011–2012,* 107 Am. J. Pub. Health 267 (2017).

¹⁴ Morgan Carpenter, *The "Normalization" of Intersex Bodies and "Othering" of Intersex Identities in Australia*, 15 J. BIOETH. INQ. 487 (2018); Georgiann Davis, Jodie M. Murphy & Erin L. Murphy, *Giving Sex: Deconstructing Intersex and Trans Medicalization Practices*, 30 GENDER & Soc. 490 (2015).

¹⁵ See, e.g., Tiffany Jones, The Needs of Students with Intersex Variations, 16 SEX. Ed. 602 (2016).

¹⁶ Amy Rosenwohl-Mack et al., *A National Study on the Physical and Mental Health of Intersex Adults in the U.S.*, 15 PLOSONE 10 (2020). *See also* CAROLINE MEDINA & LINDSAY MAHOWALD, CTR. FOR AM. PROG., KEY ISSUES FACING PEOPLE WITH INTERSEX TRAITS (2021), https://www.americanprogress.org/article/key-issues-facing-people-intersex-traits/.

experiences and set goals regarding the collection of data about intersex people in federal systems.

Lastly, in addressing disparities, it is useful to have data that allow the study of hypothesized causal factors. Using predictive models, such as the minority stress model, ¹⁷ researchers can test hypothesized causal relationships, but federal surveys often do not include factors that are required for testing of such models, such as experiences of discrimination or bullying during childhood. Some surveys do ask respondents whether they attribute a particular experience to discrimination, such as adverse employment outcomes which may be attributable to traits such as race, gender, sexual orientation, or transgender status. ¹⁸ We also see these data in some administrative records, such as complaints filed with local human rights commissions. More research needs to be done to assess measurement of experiences of discrimination and the causes or motivation for the discrimination.

(2) Are there community-based or non-Federal 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. Independent research outside of federal agencies has helped to increase the knowledge base about the factors affecting LGBT experiences. In the last decade, several datasets have been developed which focus on understanding the factors impacting the health and economic wellbeing of LGBT people that could inform the Equity Agenda, including, for example population-based and large-scale surveys such as the NIH-funded Generations and TransPop Studies, ¹⁹ as well as the community-based United States Transgender Survey. ²⁰ Data collection efforts such as these include measures of key outcomes of interest to federal agencies, as well as information on discrimination, victimization, social support, and healthcare experiences that help to better understand documented disparities.

¹⁷ See, e.g., Ilan H. Meyer, *Prejudice, Social Stress, and Mental Health in Lesbian, Gay, and Bisexual Populations: Conceptual Issues and Research Evidence,* 129 Psychol. Bull. 674 (2003); *cf.* Ilan H. Meyer, Sharon Schwartz & David M. Frost, *Social Patterning of Stress and Coping: Does Disadvantaged Social Statuses Confer More Stress And Fewer Coping Resources?* 67 Soc. Sci. & Med. 368, 371 (2008), https://pubmed.ncbi.nlm.nih.gov/18433961/(examining "social stress theory").

¹⁸ See, e.g., GENERATIONS, https://williamsinstitute.law.ucla.edu/projects/generations/ (last visited Sept. 24, 2022); TRANSPOP, https://williamsinstitute.law.ucla.edu/projects/transpop/ (last visited Sept. 24, 2022); Justice Research and Data, GOV'T OF CANADA, https://www.justice.gc.ca/eng/rp-pr/jr/index.html.

¹⁹ GENERATIONS, *supra* note 18; TRANSPOP, *supra* note 18.

²⁰ 2022 U.S. Transgender Survey, https://www.ustranssurvey.org (last visited Sept. 24, 2022).

II. Informing Data Collection

(1) Are there data collections that would be uniquely valuable in improving the Federal Government's ability to make data-informed decisions that advance equity for the LGBTQI+ community?

SOGI measures should be added to all surveys where other demographic information is collected, unless a specific reason exists not to collect such data. Collecting administrative data could raise more complex issues and require careful consideration, as described below. However, there are several administrative data collections which would benefit from inclusion of SOGI data, or the consideration of how SOGI data can be better collected for federal analytic purposes. These data collections include:

- The Adoption and Foster Care Analysis and Reporting System ("AFCARS"), which does not currently collect SOGI information and would provide information about LGBT youth in foster care, provided that the data would not be collected or reported if doing so would jeopardize the health or safety of a minor;²¹
- The National HIV Surveillance System, a state-local-federal partnership that monitors HIV trends and includes a measure of gender identity in report forms, but not sexual orientation, despite disproportionate rates of infection among men who have sex with men;²² and
- The National Violent Death Reporting System, which does collect some information related to LGBT status, but improved measures would result in better information about violent deaths of transgender people in particular.²³
- (2) To protect privacy and maintain statistical rigor, sometimes publicly released data must combine sexual and gender minority respondents into a single category. While this approach can provide valuable evidence, it can also obscure important details and differences. Please tell us about the usefulness of combined data, and under what circumstances more detailed data may be necessary.

Whenever possible, the default should be to present disaggregated information for subpopulations of LGBT people. Aggregating information may obscure important differences in the experiences of subgroups (by SOGI and/or in relation to sex assigned at birth) in the prevalence or incidence of various experiences and behaviors. For instance, poverty is more common among transgender and bisexual people than their lesbian and gay and heterosexual

²¹ See Bianca D.M. Wilson, Why We Need to Collect Data on LGBTQ Youth in Foster Care, IMPRINT (July 16, 2018), https://imprintnews.org/featured/need-collect-data-lgbtq-youth-foster-care/31619.

²² HIV and Gay and Bisexual Men: HIV Incidence, CTRS. FOR DISEASE CTRL. & PREV., https://www.cdc.gov/hiv/group/msm/msm-content/incidence.html (last visited Sept. 24, 2022).

²³ Tom W. Fouché et al., Demographic and Regional Factors Associated with Reporting Homicides of Transgender People in the United States, 279 J. SURG. RES. (2022).

counterparts,²⁴ and bisexual adults are more likely to smoke than lesbian, gay and heterosexual adults, and the inequity is pronounced among women.²⁵

Similarly, it is important to be able to disaggregate data by SOGI and race. Research has found that LGBT people of color are more likely to experience certain negative health and economic outcomes than White LGBT people as a result of marginalization along multiple identities. For example, analysis of Household Pulse Survey data revealed that more LGBT people of color experienced food insufficiency at some point during the summer or early fall of 2021, compared to non-LGBT people of color and all White respondents, regardless of LGBT status. Likewise, while only 12% of transgender people reported engaging in sex work in the 2015 U.S. Transgender Survey, that number rose to 42% among Black transgender women and about one-quarter (23%) of Latina respondents. Without disaggregation, vulnerability may be masked and intervention and resource allocation decisions could be ill-informed.

We recognize that it may be appropriate to present aggregate information in order to produce statistically reliable estimates (e.g., state-level estimates) or to look at two or more demographic characteristics simultaneously in some circumstances. However, as data amass, disaggregation (for transgender versus cisgender and LGB versus straight/heterosexual groups, at minimum, with disaggregation by race/ethnicity when possible) is recommended.

(3) Are there any Federal surveys or administrative data collections for which you would recommend the Federal Government should not explore collecting SOGI data due to privacy risk, the creation of barriers to participation in Federal programs, or other reasons? Which collections or type of collections are they, and why would you make this recommendation?

In general, there is no unique concern related to collecting SOGI data on surveys. In survey data collection, privacy protections and guidelines for "human subjects research" are clearly defined. Administrative data presents a more complicated picture, and each collection should be assessed for privacy concerns on a case-by-case basis. The NASEM panel considered the needs of agencies collecting SOGI in administrative records, and in general we recommend following the guidance laid out in the consensus report. In many ways, collecting of SOGI information is not different than other forms of sensitive information already collected by local, state, and federal agencies, such as information about race, age, and disability. An example of an agency protocol that could be applied to protect personal identifying information is the Department of Homeland Security's Fair Information Privacy Practices policy, which lays out core principles for handling sensitive data.

²⁴ BADGETT, CHOI & WILSON, *supra* note 5.

²⁵ Mostafa Shokoohi et al., *Disparities in the Prevalence of Cigarette Smoking Among Bisexual People: A Systematic Review, Meta-Analysis and Meta-Regression*, 30 Tobacco Ctrl. e78 (2020).

²⁶ CONRON ET AL., *supra* note 6.

²⁷ Sandy E. James et al., The Report of the 2015 U.S. Transgender Survey 159 (2016), https://transequality.org/sites/default/files/docs/usts/USTS-Full-Report-Dec17.pdf.

²⁸ 45 C.F.R. § 46 (2021).

²⁹ NAT'L ACADEMIES OF SCIENCES, ENGINEERING, & MED., *supra* note 2, at 9.

³⁰ Memorandum from Hugo Teufel III, Chief Privacy Officer, U.S. Dep't of Homeland Sec., The Fair Information Practice Principles: Framework for Privacy Policy at the Department of Homeland Security (Dec. 29, 2008).

However, agencies should consider additional factors when determining how to collect SOGI data in contexts other than surveys, including whether reporting jurisdictions have nondiscrimination laws in place and guarantees can be provided that disclosure will not lead to discrimination; whether reporting jurisdictions have parental notification laws or other policies that may result in the nonconsensual outing of youth, students, or others; whether there is an elevated potential for administrative SOGI data to be used to target LGBT or intersex individuals; whether individuals providing SOGI data understand all of the ways in which the data will be used; and whether individuals are able to consent to all uses of such data.

Finally, it is important to note that while LGBT people experience well-documented discrimination and disparities, we collect administrative records on other groups experiencing well-documented discrimination and disparities, such as African Americans, Indigenous people, people with disabilities, immigrants, and veterans. Individual respondents may choose not to complete this information, or to complete it in a way that minimizes their concerns about privacy. Asking SOGI questions in administrative contexts in a manner that permits individuals to decline to share their SOGI may provide the right balance.

(4) How can Federal agencies best communicate with the public about methodological constraints to collecting or publishing SOGI data? Additionally, how can agencies encourage public response to questions about sexual orientation and gender identity in order to improve sample sizes and population coverage?

Federal agencies can articulate methodological constraints related to publishing SOGI data, for instance, related to sample size, in methodical notes or technical documentation that accompanies publications including statistical tables. Sample size considerations are routine in survey research, particularly related to smaller minority populations, and federal agencies have procedures to guide the reporting or suppression of unstable estimates.³¹ Federal statistical agencies should follow standard procedures related to analysis of deductive disclosure risk and data suppression and similarly communicate decision rules in methodological notes and technical documentation.

Federal agencies can also articulate a rationale for the selection of specific measures and/or variable construction in the methodological notes and technical documentation. For instance, questions with open- versus close-ended responses may not be feasible questions on surveys with large samples. However, open-ended response options may be well-suited to community-based surveys which have smaller samples and an investigative team with appropriate knowledge to code and categorize write-in responses. Findings from community-based surveys can inform the development of close-ended response options that may be tested in general population settings and added to SOGI measures in the future.

Response rates to questions about self-reported SOGI questions are consistent with other demographic items and are higher than observed for income on surveys.³² There is no evidence

³¹ Makram Talih et al., National Center for Health Statistics Data Presentation Standards for Proportions (2017), https://www.cdc.gov/nchs/data/series/sr 02/sr02 175.pdf.

³² Cf. James M. Dahlhamer, Adena M. Galinsky & Sarah S. Joestl, Asking about Sexual Identity on the National Health Interview Survey: Does Mode Matter?, 35 J. OFF STAT. 4, 807 (2019).

to suggest that non-response is a particular problem related to SOGI measures on self-report surveys; however, it is notable that disclosure is generally higher on self-administered surveys versus those that are interviewer-administered.³³

(5) Data collection on vulnerable populations is often incomplete, creating challenges for creating data-informed decisions to advance equity for those populations. How can statistical techniques help identify missing SOGI data, and make statistically rigorous estimates for that missing data? How should qualitative information help agencies analyze what SOGI data might be missing?

Federal statistical agencies should review procedures relative to the production of sampling weights for LGBT respondents given that 1) the age, sex, and geographic distribution of the LGBT population differs from that of the general population, and 2) data sources currently used for sampling weight development (e.g., Current Population Survey) do not gather information about LGBT people.

Similarly, the Federal Government should conduct a series of tests to determine whether and how to impute missing SOGI data. Imputation issues were identified with data collected through the Household Pulse Survey, for example descriptive analyses indicate that the demographic characteristics of those classified as transgender based on imputed sex look more similar to those of cisgender respondents than to those of transgender respondents who answered the sex assigned at birth question.³⁴

III. PRIVACY, SECURITY & CIVIL RIGHTS

(1) What specific privacy and confidentiality considerations should the Subcommittee on SOGI Data keep in mind when determining promising practices for the collection of this data and restrictions on its use or transfer, especially in the context of government forms and other collections of data for programmatic use?

The federal government has data privacy protocols in place, which it utilizes when working with vulnerable populations, such as people who are incarcerated. At times, the federal government has imposed extreme measures to ensure data security, such as those administrative or survey data collected under PREA guidelines and individual-level Census data. Agencies should evaluate how to use existing protocols for sensitive data when using SOGI data, or any demographic information associated with personal identifying information.

³³ Kerith J. Conron, Matthew J. Mimiaga & Stewart J. Landers, A Population-based Study of Sexual Orientation Identity and Gender Differences in Adult Health, 100 Am. J. Pub. Health 1953 (2010); Kerith J. Conron et al., Transgender Health in Massachusetts: Results from a Household Probability Sample of Adults, 102 Am. J. Pub. Health 118 (2012).

³⁴ BILL M. JESDALE, NAT'L LGBT CANCER NETWORK, COUNTING GENDER MINORITY POPULATIONS IN THE HOUSEHOLD PULSE SURVEY (THE AGENID=2 MEMO), https://cancer-network.org/wp-content/uploads/2021/10/Counting-GM-People-in-Pulse-Data.pdf (last visited Sept. 24, 2022).

III. Conclusion

It is our position that the federal government should ensure that all surveys which contain demographic questions include SOGI measures, unless a specific reason is identified why such collection should not include these data. The federal government should also use a thorough process to implement measures to effectively identify intersex people, so that intersex disparities can be studied using federal data. Lastly, the federal government should consider administrative records on a case-by-case basis to determine how SOGI questions could be included, and how programmatic data can ethically be used to contribute to data collections.

Thank you for your consideration. Please direct any correspondence, including questions, to conron@law.ucla.edu.

Respectfully submitted,

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