

October 3, 2022

National Science and Technology Council
Subcommittee on Equitable Data
Office of Science and Technology Policy
Eisenhower Executive Office Building
1650 Pennsylvania Ave, NW
Washington, DC 20504

RE: Federal Evidence Agenda on LGBTQI+ Equity RFI

Dear Members of the Subcommittee on Equitable Data,

Rooted in LGBTQ+ liberation, Howard Brown Health provides affirming healthcare and mobilizes for social justice. Based in Chicago and serving people from all over the Midwest, we are one of the largest LGBTQ+ community health centers in the nation. We envision a future where healthcare and transformative social policies actualize human rights and equity for all. We are committed to enhancing demographic data collection on sexual orientation, gender identity, and sex characteristics (SOGISC), which is crucial to better identify and address disparities that LGBTQI+ people face. This comment addresses topics and questions related to the three pillars of the Federal Evidence Agenda: 1) describing disparities; 2) informing data collections; and 3) privacy, security, and civil rights.

1. Describing Disparities

1.1. 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?

Structural discrimination, social stigma, and lack of cultural responsiveness in the healthcare system continue to negatively impact health outcomes for LGBTQI+ people.¹ LGBTQI+ people are more likely to have chronic health problems, substance use disorders, and difficulty accessing affordable, high-quality healthcare.² We know of these disparities because of a breadth of non-Federal, community-based research and data collection efforts.

¹ National Academies of Sciences, Engineering, and Medicine, “Understanding the Well-Being of LGBTQI+ Populations” (Washington: 2020), available at <https://www.nap.edu/read/25877/chapter/1>.

U.S. Census Bureau, “American Community Survey (ACS),” available at <https://www.census.gov/programs-surveys/acs>

² National.

According to recent community-based research, LGBTQI+ people face significant economic insecurity, as well as higher rates of poverty, food insecurity, and housing instability, making this population more likely to depend on government assistance to meet basic needs.³

While scientific and community-based research on LGBTQI+ health disparities continues to grow, there are still significant gaps in our knowledge driven by lack of reliable Federal data collection. Community-based surveys do not have as wide of a reach or the ability and resources to collect larger, nationally representative sample sizes compared to Federal surveys and data collections. In this way, Federal data collection efforts are uniquely well positioned to help researchers and public health advocates better understand the unique health needs of LGBTQI+ subpopulations by generating reliable, representative data on a large scale that allows for data disaggregation.

Despite their vast reach, many Federal data collection efforts are not designed to fully assess LGBTQI+ health disparities because many do not collect sexual orientation, gender identity, and sex characteristics (SOGISC) data. This limits our ability to identify and address the challenges that LGBTQI+ people face, such as discrimination and resulting disparities in health outcomes and access to Federally funded programs and services. Unfortunately, surveys that do include SOGI data collection often aggregate data, skewing many important statistics and obscuring unique health concerns and needs for different LGBTQI+ communities. One specific subpopulation that is completely overlooked are those with intersex characteristics, as no Federal survey ask questions that can identify people with intersex traits. Considering this, many disparities faced by LGBTQI+ subpopulations are not well understood through existing Federal statistics.

Understanding the obstacles that LGBTQI+ people face when seeking healthcare, housing, insurance, or benefits is critical to addressing these disparities. Areas frequently overlooked in Federal data collection efforts when it comes to LGBTQI+ communities include access to basic needs and benefits, public health surveillance for current and potential epidemics, and information to better understand the needs of intersex people. While more Federal surveys are attempting to collect SOGI data, many of these surveys allow for the SOGI collection modules to be optional. Federal data collection efforts that should prioritize and require standardized SOGISC data collection, particularly in response to these well-known disparities, are listed under Question 2.

³ Rosenwohl-Mack A, Tamar-Mattis S, Baratz AB, Dalke KB, Ittelson A, Zieselman K, et al. (2020) A national study on the physical and mental health of intersex adults in the U.S. PLoS ONE 15(10): e0240088; Caitlin Rooney, Charlie Whittington, and Laura E. Durso, "Protecting Basic Living Standards for LGBTQ People" (Washington: Center for American Progress, 2018), <https://www.americanprogress.org/issues/lgbtq-rights/reports/2018/08/13/454592/protecting-basic-living-standards-lgbtq-people/>

1.2. 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?

There are many organizations, including the Williams Institute,⁴ Trevor Project,⁵ GLSEN,⁶ and the Center for American Progress (CAP)⁷ that collect important and high-quality data from the LGBTQI+ community that could be helpful in the creation of the Federal Evidence Agenda. Each of these organizations regularly performs community-based data collection that can be incredibly beneficial in understanding disparities that LGBTQI+ people experience in health outcomes, discrimination in schools, interpersonal violence, substance abuse, housing instability and homelessness. Due to their specific focus on sampling underrepresented LGBTQI+ populations, these community-based surveys are especially beneficial in increasing the Federal Government's ability to make data-informed decisions that promote equity for the most vulnerable among the LGBTQI+ community. For example, these organizations gather data on LGBTQI+ people who are also people of color, older adults, youth, people with disabilities, people receiving social welfare support services, people whose primary language is not English, and people interacting with the criminal justice system more easily due to the history of advocacy and rapport built within the LGBTQI+ community. These community-based surveys often include more non-binary response options,⁸ allowing survey respondents to self-identify and write in their preferred response if not listed. This can provide valuable opportunities to learn more about even smaller or less-studied sexual and gender minority populations, such as asexual and Two-Spirit populations. The U.S. Trans Survey is a particularly good example of survey questions and response options informed by that trans community.⁹ These survey methodologies for reaching typically understudied LGBTQI+ populations would be good for the Federal Evidence Agenda to incorporate.

⁴ Data Collection. Publications. Williams Institute, UCLA. <https://williamsinstitute.law.ucla.edu/issues/data-collection/>

⁵ Latest Research. The Trevor Project. <https://www.thetrevorproject.org/research/>

⁶ Reports and Briefs. GLSEN. <https://www.glsen.org/research/reports-and-briefs>

⁷ Medina, C., Mahowald, L. (2022). [Collecting Data About LGBTQI+ and Other Sexual and Gender-Diverse Communities: Best Practices & Key Considerations Report](https://www.americanprogress.org/article/collecting-data-about-lgbtqi-and-other-sexual-and-gender-diverse-communities/). Restoring Social Trust in Democracy. Center for American Progress, Washington, D.C. <https://www.americanprogress.org/article/collecting-data-about-lgbtqi-and-other-sexual-and-gender-diverse-communities/>

⁸ Medina, C.

⁹ NCTE. <https://www.ustranssurvey.org/>

As mentioned in Section 1.1, while community-based surveys are extremely helpful for understanding LGBTQI+ health disparities, all disparities could be better understood and addressed through Federal statistics and data collection.

1.3. 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?

In reflecting on policy research priorities, the Subcommittee should prioritize adding SOGISC to Federal data collection efforts that would help us better understand structural barriers to care and social determinants of health. The impacts of systemic discrimination are not well understood in Federal surveys and data collection. According to a 2020 national survey conducted by the Center for American Progress,¹⁰ more than one-third of LGBTQI+ adults experienced discrimination in the previous year, including more than two-fifths of LGBTQI+ people of color and more than three-fifths of transgender people. LGBTQI+ people face discrimination in accessing health insurance, employment, housing, marriage, adoption, and retirement benefits. Federal data collection could help us better understand how discrimination may be impacting LGBTQI+ people's access to Federal assistance programs and resources in each of these areas.

Another important policy priority area is public health surveillance, especially as our country continues to face the Covid-19 pandemic and the Monkeypox Virus outbreak. Lack of consistent SOGISC data collection in our public health surveillance and safety net healthcare systems makes it difficult to fully understand how new public health emergencies impact LGBTQI+ communities, which in turn leads to lack of coordinated efforts to aid LGBTQI+ communities.

Informing Data Collections

2.1. In some instances, there are multiple surveys or data collections that could be used to generate evidence about a particular disparity faced by the LGBTQI+ community. In addition to factors like sample size, timeliness of the data, and geographic specificity of related data publications, what other factors should be considered when determining which survey would best generate the relevant evidence? 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?

¹⁰ Mahowald, L., Gruberg, S., Halpin, J. State of the LGBTQ Community in 2020. A National Public Opinion Study. October 2020. <https://www.americanprogress.org/wp-content/uploads/2020/10/LGBTQpoll-report.pdf>

Many Federal data collections—especially those related to access and use of Federal programs and benefits, healthcare services, and health insurance—could provide valuable information on LGBTQI+ communities. The aforementioned disparities impacting LGBTQI+ people’s health, livelihood and basic needs could be best assessed if the following Federal departments collected more thorough SOGISC data:

- The Centers for Medicare & Medicaid Services (CMS) should prioritize SOGISC data collection on Medicare, Medicaid, and healthcare marketplace surveys and Supplemental Nutrition Assistance Program (SNAP) application forms. According to a study by the Center for American Progress,¹¹ one in five gay and bisexual men and one in four lesbian and bisexual women are living in poverty. Rates of poverty are also especially high among transgender people of color. Due to these high rates of poverty, LGBTQI+ people could disproportionately benefit from CMS programs for low-income Americans like Medicaid and SNAP. Collecting SOGISC information from program applicants and participants will allow CMS to assess if they are doing a good job of reaching LGBTQI+ communities who need these services.
- The Department of Commerce (DOC) should collect SOGISC data in the following surveys:
 - The American Community Survey (ACS) collects vital information about people's social, economic, housing, and demographic characteristics from 3.5 million addresses across the country each year, but it does not consistently account for LGBTQI+ people. Incorporating SOGISC measures into the ACS will yield more accurate data for assessing LGBTQI+ people's economic security. Since ACS data is used to determine funding allocations, more accurate SOGISC data can inform more equitable policies for allocating resources to vulnerable communities.
 - The Survey of Income and Program Participation (SIPP) collects comprehensive information about income, family dynamics, access to education and health insurance, food security, childcare, and use of government assistance programs. SIPP overlooks LGBTQI+ people, which impedes our understanding of financial stability and participation in government programs among LGBTQI+ communities. This data could help us determine whether these programs are meeting the needs of LGBTQI+ people, and if not, how these programs and resources can be made more accessible.

¹¹ Baker, K.E., McGovern, A., Gruberg, S., and Cray, A. (2016) The Medicaid Program and LGBT Communities. Overview and Policy Recommendations. Center for American Progress, Washington, D.C. <https://www.americanprogress.org/wp-content/uploads/2016/08/2LGBTMedicaidExpansion-brief.pdf>

- The Current Population Survey (CPS) collects information on wages, employment, and labor force participation monthly. The data is used to generate labor market demographic reports, but without SOGISC data in the CPS, these demographic reports do not reflect the experiences of LGBTQI+ workers. SOGISC questions must be included in the CPS to better identify labor market trends and the experiences of LGBTQI+ people, especially given the high rates of employment discrimination experienced by this community.
- The Department of Health and Human Services (HHS) should make SOGISC measures permanent in the following surveys:
 - The National Health Interview Survey (NHIS) collects national data to track health-related trends, identify barriers to care, and allow researchers to analyze health-related behaviors and insurance coverage. In these areas, LGBTQI+ communities face significant disparities. Questionnaires that allow people with intersex traits to be identified are especially important for better understanding and resolving health disparities for people with intersex traits.
 - The Behavioral Risk Factor Surveillance System (BRFSS) collects state health and risk behavior data, serving as the largest source of population-based sexual orientation data and the only source of population-based gender identity data available by state. However, the BRFSS does not currently collect data on intersex people, which could provide important insights into disparities. SOGISC measures must be standardized within demographic questionnaires used by every state in order to collect valid national data that can best inform health policy. This would provide valuable information on health and risk behavior among LGBTQI+ populations across the country. Further, this data would be beneficial in assessing health outcomes and risk behaviors among LGBTQI+ populations in different states, especially since some states have recently proposed legislation to restrict access to gender-affirming and reproductive healthcare.
 - The Youth Risk Behavior Surveillance System (YRBSS) collects data on health behaviors and the leading causes of death and disability among children and adolescents. The YRBSS does collect sexual orientation data, which has revealed stark mental health disparities among LGBQ students, such as high prevalence of depression and increased rates of suicidal ideation. Gender identity and intersex traits questions must be added to the standard questionnaire to assess and monitor the health and well-being of all LGBTQI+ youth.

- The National Violent Death Reporting System (NVDRS) should also collect SOGISC data as it can inform interventions to understand and prevent the occurrence of violent deaths in the United States. This data collection would benefit all LGBTQI+ people, but especially youth who are at increased risk of suicide due to harassment and discrimination,¹² as well as transgender women, particularly transgender women of color, who face increased levels of violence.¹³
- The Department of Housing and Urban Development (HUD) should add SOGISC data collection within the American Housing Survey (AHS). The AHS could be very beneficial to understanding the prevalence of housing insecurity among LGBTQI+ communities by including SOGISC questions when collecting information on the size, cost, composition, and quality of housing in the United States. These statistics aid in informing decisions that affect housing opportunities for people across the country and can be used to advance efforts to ensure HUD programs equitably serve LGBTQI+ people.
- All Federal agencies should prioritize SOGISC data collection on civil rights enforcement forms. In light of the *Bostock v. Clayton County* decision, it is more apparent than ever that SOGISC data must be collected to evaluate outcomes driven by economic marginalization and social discrimination that many LGBTQI+ people endure to enforce civil rights protections.

2.2. 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.

While combining SOGISC data can provide useful insights and is certainly preferable to having no data, it can hide disparities that differ by sexual orientation, gender identity, or intersex status. Disaggregating data should be prioritized due to the unique needs of subpopulations within the LGBTQI+ community. For example, the LGBTQI+ population as a whole has high rates of chronic disease such as cardiovascular disease and cancer; however, each subpopulation has different rates and risk factors. According to studies, Black, bisexual, and transgender people have a higher prevalence of cardiovascular disease

¹² The Trevor Project. “2022 National Survey on LGBTQ Youth Mental Health”

<https://www.thetrevorproject.org/survey-2022/>

¹³ Human Rights Campaign. “An Epidemic of Violence 2022”, available at <https://reports.hrc.org/an-epidemic-of-violence-fatal-violence-against-transgender-and-gender-non-confirming-people-in-the-united-states-in-2021>

than white lesbian women.¹⁴ Other studies have found that the incidence of certain cancers, such as anal cancer in gay and bisexual men, and breast cancer in lesbian and bisexual women, may be higher in specific LGBTI populations.¹⁵ Aside from health disparities, factors around income and housing stability can often be overlooked by aggregated data. A Williams Institute report highlights that poverty rates can differ significantly between LGBTQI+ subpopulations, with 12.1% of cis gay men, 17.9% of cis lesbians, 19.5% of cis bisexual men, 29.4% of cis bisexual women, 29.6% of transgender women, and 33.7% of transgender men experiencing poverty.¹⁶ Similarly, there is little data on disparities affecting intersex people due to this population either not having an accurate option to choose on surveys or the population's data being combined with the entirety of the LGBTQI+ population. We understand that to maintain statistical rigor, Federal agencies may be required to report aggregated data, especially earlier on in the process of SOGISC data collection. However, we encourage Federal agencies to use strategies like pooling disaggregated data from multiple collections to allow for more comprehensive analysis on LGBTQI+ subpopulations.

2.3. 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?

It is critical that the Federal government collect SOGISC data to best document and address LGBTQI+ health disparities. This data can be collected effectively and safely by utilizing legal safeguards and best practices for data collection and protecting respondent privacy and confidentiality that are already in place for other Federal surveys and data collections.

2.4. 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?

¹⁴ Caceres, B.A., Brody, A., Luscombe, R.E., Primiano, J.E., Marusca, P., Sitts, E.M., and Chyun, D. (2017). A systematic review of cardiovascular disease in sexual minorities. *American Journal of Public Health*, 107(4), e13–e21. doi: 10.2105/AJPH.2016.303630a.

¹⁵ Quinn, G.P., Sanchez, J.A., Sutton, S.K., Vadaparampil, S.T., Nguyen, G.T., Green, B.L., Kanetsky, P.A., and Schabath, M.B. (2015). Cancer and lesbian, gay, bisexual, transgender/transsexual, and queer/questioning (LGBTQ) populations. *CA: A Cancer Journal for Clinicians*, 65(5), 384–400.

¹⁶ Badgett, M.V. Lee., Choi, Soon Kyu., Wilson, Bianca D.M. LGBT Poverty in the United States: A study of differences between sexual orientation and gender identity groups. (2019). The Williams Institute, UCLA. <https://escholarship.org/content/qt37b617z8/qt37b617z8.pdf>

Federal agencies can best communicate with the public by being transparent about the methodological constraints, how the data may be impacted, and how the data can be used and/or supplemented to present a more realistic picture of the survey population. In order to encourage public response to improve sample size, Federal agencies should develop surveys and data collection tools alongside the population that is being studied to ensure that the language used is culturally appropriate, accessible, and consistent. We also recommend that Federal agencies meaningfully engage in conversations with LGBTQI+ community leaders about how the agency can decrease LGBTQI+ stigma, ensure privacy of information, and translate SOGISC terms in a way that aligns with community cultural and language norms.¹⁷ We also recommend that agencies train all staff involved in SOGISC data collection in LGBTQI+ culturally responsive and affirming care and language.¹⁸

3. Privacy, Security, and Civil Rights

3.1. While the confidentiality of data collected by the statistical system is protected by statute, OMB and other agency policies, and experience in protecting the confidentiality of respondents through data governance, privacy-preserving technology, and disclosure limitation practices, a wide range of privacy protections apply to data collected for programmatic purposes, such as applications for Federal programs or benefits, compliance forms, human resources data, and other data used to manage and operate Federal programs. 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?

It is critical that LGBTQI+ respondents feel comfortable and safe disclosing SOGISC data in Federal data collection instruments. Luckily, the Federal government already has robust privacy and confidentiality legal requirements around demographic data collection, such as the Health Insurance Portability and Accountability Act. Wherever SOGISC data is collected, analyzed, and stored in Federal data collection initiatives, it should be treated with the same safeguards and robust privacy protections that already exist for other potentially sensitive data. Federal agencies should also share guidance and best practices for strategies and workflows that enhance privacy and data security and reduce risk of unintentional outing. For example, it would be helpful for agencies to research and share strategies for effectively de-identifying SOGISC data, workflows for collecting SOGISC data that enhance privacy (i.e., electronic self report), and best practices for obtaining consent for the

¹⁷ https://www.lgbtqihealtheducation.org/wp-content/uploads/2022/05/TFIE-64_Updates2022_ReadySetGo-FINAL.pdf

¹⁸ https://assets2.hrc.org/files/assets/resources/Tip_Sheet_for_Collecting_SOGI_Data.pdf

transmission of SOGISC data. Prior to any data collection, it is also imperative that respondents are informed in plain language how the data will be protected, what it will be used for, and who will have access to identified and de-identified data. All this being said, it is important to note that SOGISC data collection should not be thought of as uniquely difficult or burdensome to protect compared to other demographic data.

3.2. Unique risks may exist when collecting SOGI data in the context of both surveys and administrative forms. Please tell us about specific risks Federal agencies should think about when considering whether to collect these data in surveys or administrative contexts.

There is a potential risk that improper disclosure of SOGISC data can cause harm and expose participants to discrimination. This is especially true for data collections where responses are mandatory and/or data is used in conjunction with personally identifiable information. However, similar risks exist for other types of routinely collected demographic data and there are best practices and safeguards in place to protect such data. We urge Federal agencies to ensure that administrative data collection on SOGISC is collected in a way that minimizes risk of discrimination and upholds robust privacy and confidentiality standards. This can include adopting strong protocols for de-identifying and anonymizing data, destroying identifiable data within a set time period, collecting and maintaining this data separate from individual identifying records, and imposing strict restrictions on who is able to view, use, and share this data.

3.3. Once SOGI data have been collected for administrative or statistical purposes, are there considerations that Federal agencies should be aware of concerning retention of these data? Please tell us how privacy or confidentiality protections could mitigate or change these concerns.

Federal agencies already have strong protocols in place for retaining sensitive data in a safe and confidential manner. For example, the CDC has guidance on data collection, storage, sharing, and use to ensure security and confidentiality. As mentioned previously, we recommend: adopting strong protocols for de-identifying and anonymizing data, destroying identifiable data within a set time period, collecting and maintaining this data separate from individual identifying records, and imposing strict restrictions on who is able to view, use, and share this data.

3.4. Where programmatic data is used to enforce civil rights protections, such as in employment, credit applications, or education settings, what 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?

Civil rights protections and enforcement is an especially important use for SOGISC data given the aforementioned research showing high levels of anti-LGBTQI+ discrimination in health care, employment, housing, public accommodations, schools, and other areas of everyday life. It is especially important to reinforce and uphold rigorous confidentiality and privacy standards for civil rights complaints considering that the potential for misuse of this data and additional discriminatory action is heightened. Federal agencies should make sure that people who are filing civil rights complaints understand why SOGISC data is collected, how the data will be used, and what restrictions are in place to safeguard access to the data.

Conclusion

We thank you for your interest in advancing SOGISC data collection. We encourage the Administration to expand and enhance SOGISC data collection as highlighted above to ensure that Federal agencies are able to make meaningful progress on their goal to advance LGBTQI+ health equity. Thank you for your consideration. If you have any questions feel free to reach out to Tim Wang, Director of Policy and Advocacy, at timothyw@howardbrown.org.

Sincerely,

David Ernesto Munar
President and CEO