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,

On behalf of 106 organizations dedicated to improving the wellbeing of lesbian, gay, bisexual, transgender, queer, intersex and other sexual and gender minority (LGBTQI+) people, we write in response to the Office of Science and Technology Policy's request for information (RFI) to help develop the Federal Evidence Agenda on LGBTQI+ Equity (87 FR 52083).[1]

Our organizations are committed to enhancing demographic data collection on sexual orientation, gender identity, and variations in sex characteristics (SOGISC), which is crucial to better identify and address the disparities that LGBTQI+ people face, as well as to assess how the government is progressing in its mission to meaningfully advance LGBTQI+ equity. We strongly support the Biden-Harris administration's mission to create a Federal Evidence Agenda on LGBTQI+ Equity and appreciate the opportunity to provide feedback on this process.

This comment addresses topics and questions related to all three pillars of the Federal Evidence Agenda on LGBTQI+ Equity set forth in Executive Order 14075 and in the RFI: (1) describing disparities; (2) informing data collections; and (3) privacy, security, and civil rights. While the RFI seeks input on many questions, this comment speaks to a select few which are clearly labeled below.

1. Disparities faced by LGBTQI+ individuals could be better understood through Federal statistics and data collection

Question 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?

Existing research reveals that LGBTQI+ people face disparate and inequitable treatment, which adversely affects outcomes across key areas of everyday life, including health status; access to health care and health insurance; economic and housing security; educational attainment; and family and social support.[2] For instance, existing research shows that LGBTQI+ people are more likely to have chronic health conditions, to have substance use disorders, and to lack access to affordable, quality health care.[3] Importantly, the health of LGBTQI+ communities is severely impacted by discrimination, stigma, prejudice, as well as other social determinants of health.[4] Recent studies also reveal that LGBTQI+ people experience substantial economic insecurity. For example, LGBT people experience higher rates of poverty, food insecurity, homelessness and housing instability, and are more likely to use public benefits to help meet basic living standards.[5]

While existing research shows that LGBTQI+ people experience health, economic, and housing disparities compared with non-LGBTQI+ people, evidence also demonstrates that disparities are often more pronounced for transgender individuals,[6] LGBTQI+ people of color,[7] LGBTQI+ people with disabilities,[8] LGBTQ youth[9] and LGBTQI+ older adults.[10] For example, Black and Latinx LGBT people are more likely than white LGBT people to live in low-income households, experience food insecurity, and be unemployed.[11] There is also evidence that LGBT people are more likely to report having a disability[12] and there is a higher representation of people of color in LGBTQ communities.[13]

Although knowledge of the disparities that LGBTQI+ communities face has increased in recent years, significant gaps – driven by lack of reliable data – remain. Much of the evidence base relies on data gathered through community or non-Federal statistics or data collection. A dearth of consistent, large-scale SOGISC data collection by federal and state governments poses a barrier to obtain adequate data about the diversity of LGBTQI+ experiences and to better comprehend and address disparities. More reliable, quality data that allow for disaggregation by sexual orientation, gender identity, variations in sex characteristics, race, ethnicity, disability, age and other key demographic variables are needed to better understand the experiences of those living at the intersections of multiple marginalized identities. A more detailed list of priority data collections is provided in Section 2 of this comment.

Often, the data collection mechanisms of Federal agencies may be the only systems capable of gathering information from particular populations about a wide range of subjects.[14] Indeed, the Federal government is uniquely well-positioned to engage in data collection in a way that will generate accurate, consistent, and representative data at a scale that allows for data disaggregation that is crucial for intersectional analyses of disparities faced among different LGBTQI+ communities and to evaluate progress in the government's goal of advancing equity.[15] For these reasons, we firmly support the development of the Federal Evidence Agenda and the Office of Management and Budget issuing strong and meaningful guidance to federal agencies on best practices for collecting SOGISC demographic data, as outlined in Executive Order 14075.

Question 1.3 What factors or criteria should the Subcommittee on SOGI Data consider when reflecting on policy research priorities?

Expanding and enhancing SOGISC data collection is critical to bring visibility to the experiences of LGBTQI+ communities, for example, with respect to accessing needed medical care, good-paying jobs, or secure housing. When reflecting on policy research priorities, the Subcommittee should prioritize adding SOGISC measures to data collections that will deepen our understanding of LGBTQI+ population trends with respect to experiences of poverty, unemployment, use of public benefits, food insecurity, housing instability, experiences of violence, health status, access to care and insurance coverage, and behavioral risk. Data collections that provide valuable information about trends and patterns of these outcomes for LGBTQI+ people, allow researchers to generate accurate estimates about the size of the LGBTQI+ population, and provide data that can be used to target resources, evaluate programs or services, and enforce nondiscrimination protections are of particular importance. A more detailed list of priority survey mechanisms is provided in Section 2.

2. Improved SOGISC data collection is important for advancing the Federal Government's ability to measure disparities facing LGBTQI+ individuals

Question 2.1 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?

As indicated above, existing evidence shows that LGBTQI+ communities face significant disparities especially with respect to health status, economic security, and housing stability. There are data collections that would be uniquely valuable in improving the Federal government's ability to make data-informed decisions that advance equity for LGBTQI+ people in these areas. Below is a list of high-priority Federally supported survey instruments where we encourage the Subcommittee to take swift and meaningful action to add best-practice SOGISC measures. We recommend that:

- The U.S. Department of Commerce add SOGISC measures to the American Community Survey (ACS). This ongoing household-based survey of 3.5 million addresses a year collects crucial information about the social, economic, housing, and demographic characteristics of people across the country.[16] Lack of SOGISC measures on the ACS results in significant gaps: It is estimated that more than 5 in 6 LGBT adults cannot be identified by existing questions on the ACS and decennial census, which only account for cohabitating same-sex couples.[17] Single LGBQ people, transgender and intersex adults cannot be identified at all. As noted in the 2022 National Academies of Sciences, Engineering, and Medicine's (NASEM) report on *Measuring Sex, Gender Identity, and Sexual Orientation*, the absence of SOGISC measures on the decennial census or ACS mean that "there is no "gold standard" against which data collections can perform weighting adjustments or assess data quality and nonresponse bias for LGBTQI+ populations.[18]" Moreover, ACS data shape major policy decisions, help to guide allocations of approximately $1.5 trillion in federal funding annually, provide geographic-specific information that shed light on how experiences vary across states and localities, and are used to enforce nondiscrimination laws. [19] Multiple agencies - including the U.S. Department of Justice, U.S. Department of Health and Human Services, and U.S. Department of Housing and Urban Development - have recognized the programmatic and legal need for the collection of these data on the ACS.[20] We urge the Biden-Harris administration to revitalize these efforts to add SOGISC questions to the ACS to ensure that the needs and experiences of LGBTQI+ communities are reflected in government policies, programs, and funding investments that derive from ACS data.

- The U.S. Department of Commerce add SOGISC measures to the Survey of Income and Program Participation (SIPP). This longitudinal survey collects important panel data on income, employment, household composition, and participation in government programs and is a leading source of data on economic well-being, family dynamics, education, wealth, health insurance, child care, and food security.[21] Survey results are used to evaluate changes to and effectiveness of programs (e.g., the Supplemental Nutrition Assistance Program), changes in income, movement into and out of government assistance programs, changes in family composition and social conditions, as well as changes in health, health insurance coverage, and access to health care.[22] In addition to national surveys, many administrative forms lack SOGISC questions, hindering the ability to measure rates of LGBTQI+ people participating in government programs. Adding SOGISC questions to SIPP is especially useful because it would result in a major source of survey data providing information about how LGBTQI+ people access government benefits across a wide range of different programs. At the same time, it is imperative for individual agencies to add these measures to administrative forms for individual programs.

- The U.S. Department of Commerce and the U.S. Department of Labor add SOGISC measures to the Current Population Survey (CPS). This monthly survey collects crucial information about employment and unemployment; emerging trends in employment status, wages, and earnings; and variables affecting labor force participation.[23] Every month the Bureau of Labor Statistics uses these data to publish monthly Employment Situation reports about how the labor market is progressing across different industries and for different demographic groups. Adding SOGISC questions to the CPS is essential to shed light on the monthly labor market experiences of LGBTQI+ communities, so researchers and policymakers can identify trends or patterns.

- The U.S. Department of Health and Human Services make permanent measures of gender identity and add questions that allow for the identification of people with intersex traits on the National Health Interview Survey (NHIS). The cross-sectional NHIS survey generates nationally representative data used to monitor trends in health status, identify barriers to accessing care, and assess progress to achieving national health objectives. [24] The NHIS provides crucial information that allow researchers and the government to examine health status, analyze health behaviors, and track health insurance coverage, areas where LGBTQI+ communities face substantial disparities. Adding questions that allow for the identification of people with intersex traits is crucial to better understand and remedy health disparities for people with intersex traits, many of which are driven by nonconsensual, medically unnecessary interventions to alter natural variations in genital appearance or reproductive anatomy.[25]

- The U.S. Department of Health and Human Services work with state coordinators to add SOGISC questions to the standardized demographic core questionnaire of the Behavioral Risk Factor Surveillance System (BRFSS). BRFSS collects state health and risk behavior data, offering the largest source of population-based sexual orientation data and the only source of population-based gender identity data and serving as the only source of these data available by state.[26] BRFSS currently collects no data enabling identification of intersex people, but could provide crucial insights on demographics and disparities. In 2020, 32 states and Guam used the sexual orientation and gender identity optional question modules, but these measures are not part of the standardized demographic core questionnaire that every state uses each year.[27] Adding SOGISC questions to the standardized demographic core questionnaire would enhance consistency and improve data validity and the ability to make national-level inferences from the dataset.[28] Doing so would also provide invaluable data on health and risk behavior among LGBTQI+ populations across the country and within particular states, which is of particular importance given recent actions by states to restrict access to gender-affirming, reproductive, and other kinds of health care.

- The U.S. Department of Health and Human Services support the addition of questions on gender identity and that allow for the identification of people with intersex traits to the standard Youth Risk Behavior Surveillance System (YRBSS) questionnaire. The YRBSS monitors health behaviors and experiences that contribute to the leading causes of death and disability among young people.[29] For example, these data have revealed negative mental health outcomes among LGBQ students, including depression, increased rates of considering and attempting suicide. Adding questions on gender identity and that allow for the identification of people with intersex traits to the standard questionnaire is especially important to assess and monitor the health and wellbeing of LGBTQI+ youth in light of recent legislative attacks on LGBTQI+ youth.[30]

- The U.S. Department of Health and Human Services implement policies and procedures to require the collection of SOGISC data within the National Violent Death Reporting System (NVDRS). The NVDRS is the only state-based surveillance reporting system that pools more than 600 unique data elements from multiple sources into an anonymous database on all types of violent deaths – including those due to suicide or homicide – in all settings for all age groups.[31] Implementing policies and procedures to add SOGISC measures to the NVDRS is vital to inform interventions to better understand and prevent the occurrence of violent deaths in the United States. Such interventions are crucial for all LGBTQI+ people, but especially LGBTQI+ youth who are at increased risk for suicide due to mistreatment and stigmatization,[32] as well as transgender women – especially transgender women of color – who continue to face epidemic levels of violence.[33]

- The U.S. Department of Housing and Urban Development add SOGISC questions to the American Housing Survey (AHS). As the most comprehensive national housing survey in the country, the AHS provides important information on the size, composition, cost, and quality of housing in the U.S. These data inform decision-making that impacts housing opportunities for people across the country. Adding SOGISC questions to the AHS will allow researchers to better comprehend the prevalence of housing insecurity among LGBTQI+ communities, the intersection of race and ethnicity and other demographic variables, and advance efforts to ensure HUD programs equitably serve LGBTQI+ people.

There are also multiple administrative data collections that would provide distinctly valuable information on LGBTQI+ communities, for example, those related to access and use of federal programs and benefits, as well as health care services and insurance. Beyond understanding the prevalence of disparities, collecting SOGISC data through these collections will help advance specific, targeted interventions and promote culturally competent, responsive social services. We urge the Centers for Medicare and Medicaid Services to prioritize collecting SOGISC data on application forms for Medicare, Medicaid, and federally-facilitated marketplaces, and the Administration for Children and Families to collect SOGISC data through the Adoption and Foster Care Analysis and Reporting System. Additional priority administrative data collections include gathering SOGISC information through application forms for the Supplemental Nutrition Assistance Program and collecting SOGISC data for the purposes of civil rights enforcement, especially in light of the *Bostock v. Clayton County* decision.[34]

Collecting reliable, quality data on SOGISC through these mechanisms will allow the Federal government to better measure and address disparities, resulting in better, evidence-based decision-making and policymaking. Doing so is crucial to evaluate outcomes driven by discrimination, as well as the economic and social marginalization that many LGBTQI+ people continue to experience.

Question 2.2 Please tell us about the usefulness of combined data, and under what circumstances more detailed data may be necessary.

The RFI notes that sometimes publicly-released data must combine sexual and gender minority respondents into a single category in order to protect privacy and maintain statistical rigor with respect to sample size and other important factors. We agree that this approach may mask important details and differences about outcomes that vary by sexual orientation, gender identity, or intersex status and whenever possible disaggregating data according to these demographics should be prioritized. When that is not possible, combined data can still provide valuable evidence and is preferable over not reporting any data, which erases the experiences of LGBTQI+ communities from the dataset entirely. In particular circumstances federal agencies may initially have to report combined data to maintain statistical rigor but then have the opportunity to pool data over the course of multiple collections in a way that allows for stratification on participants' sexual orientation, gender identity, and variations in sex characteristics. When that is an option, we support federal agencies taking this approach and making these data publicly available so that more detailed analyses on subpopulations within the larger LGBTQI+ population can be performed.

Question 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?

Federal agencies should clearly communicate with the public about methodological constraints to collecting or publishing SOGISC data both in technical documentation tied to public use datasets, as well as in plain language on their websites so that the information is readily available for a wide range of audiences. To encourage public response to questions about sexual orientation, gender identity, and variations in sex characteristics, and in turn improve sample sizes and population coverage, federal agencies should also provide public materials that address frequently asked questions about the use of the data; nondiscrimination protections; privacy, security, and confidentiality standards; restrictions on data sharing and other topics. Agencies should also work in partnership with organizations representing and serving LGBTQI+ populations in order to support effective awareness initiatives, as well as public and community education campaigns.[35]

3. It is essential to identify practices for all agencies engaging in SOGISC data collection to adopt in order to safeguard privacy, security, and civil rights

Question 3.1 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?

It is crucial that all respondents - including LGBTQI+ respondents - feel confident that their data will be protected and not subject to misuse. During every phase of analysis and dissemination, SOGISC data must be analyzed, maintained, and shared only with rigorous privacy and confidentiality standards in place and upheld. We urge federal agencies to protect the privacy and confidentiality of LGBTQI+ respondents across all data collections that gather demographic information on SOGISC consistent with existing legal requirements (e.g., the Health Insurance Portability and Accountability Act and the Paperwork Reduction Act) and Fair Information Practice Principles.[36] Where these data are collected, agencies should issue guidance and technical assistance outlining how to safeguard privacy and confidentiality, implement best practices of consent for the collection of these data, and adopt appropriate restrictions on their use, sharing, or transfer. As noted above, these privacy and confidentiality policies should be clearly shared in plain language with respondents to promote transparency about the uses and non-uses of these demographic data. At the same time, OMB and agencies should make clear that there should be no presumption that such considerations make SOGISC data collection uniquely difficult or prohibitive.

Question 3.2 Please tell us about specific risks Federal agencies should think about when considering whether to collect these data in surveys or administrative contexts.

The RFI notes that specific risks exist when collecting SOGISC data in surveys or administrative contexts and we support SOGISC data collection in both contexts in a way that maintains statistical rigor, as well as robust privacy, confidentiality, and security standards. The 2022 NASEM report found that SOGISC data should be routinely collected in three core settings: surveys and research studies, administrative settings, and in clinical contexts and provides evidence to support adding SOGISC measures, accounting for differences related to the uses of data, identifiability of respondents, and the risk of data disclosure in each context.[37] In particular, the report finds that the federal government is well-positioned to expand and enhance demographic data collection on SOGISC in population surveys where data are often collected in aggregate with strong protections in place to maintain privacy and confidentiality, thereby reducing the risk of disclosure and enabling routine collection of data to identify and better serve LGBTQI+ populations.

While evidence shows SOGISC questions are not especially sensitive,[38] certain administrative and programmatic settings, there may be heightened risk of disclosure or misuse. This is especially true where a response is mandatory, is used as personally identifiable information (PII), or both. 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, including adopting strong protocols for anonymizing the collected data, destroying personally identifiable data at the appropriate time, collecting and maintaining these data separately from individual records for aggregate statistical purposes, and imposing appropriate restrictions on the use, sharing, or transfer of these data.

4. Conclusion

Our organizations are unified in our strong support for the Biden-Harris administration to engage in comprehensive SOGISC data collection in order to meaningfully advance its Federal Evidence Agenda on LGBTQI+ Equity. We encourage the administration to expand and enhance SOGISC data collection on the priority mechanisms highlighted above and to ensure that federal agencies receive adequate guidance, staffing, and funding to effectively operationalize the implementation of these data collections.

Thank you for your consideration. Please do not hesitate to contact Caroline Medina, cmedina@americanprogress.org, if you need any additional information.

Sincerely,

National organizations:

2020 Mom
Advocates for Youth
American Academy of Social Work and Social Welfare
American Public Health Association
Anxiety and Depression Association of America
Arab American Institute
Autistic Self Advocacy Network
Bayard Rustin Center for Social Justice
Big Cities Health Coalition
Center for American Progress
Center for LGBTQ Economic Advancement & Research (CLEAR)
CenterLink: The Community of LGBT Centers
Diversity Center of Oklahoma Inc.
Empowering Pacific Islander Communities
Encircle Therapy & Encircle: LGBTQ Youth and Family Resource Center
Equality Federation
Family Equality
FORGE, Inc.
GLSEN
Hispanic Federation
Human Rights Campaign
Insights Association
Inter-university Consortium for Political and Social Research (ICPSR)
interACT: Advocates for Intersex Youth
JACL
Justice in Aging
Lawyers for Good Government (L4GG)
LGBTQ+ & Equity Consulting, LLC
MAZON: A Jewish Response to Hunger
Minority Veterans of America

Movement Advancement Project
National Black Justice Coalition
National Center for Lesbian Rights
National Center for Transgender Equality
National Council of Asian Pacific Americans (NCAPA)
National Health Law Program
National LGBT Cancer Network
National LGBTQ Task Force
National Partnership for Women & Families
National Women's Law Center
Planned Parenthood Federation of America
Prison Policy Initiative
Restaurant Opportunities Centers United
SAGE
Shriver Center on Poverty Law
The Leadership Conference on Civil and Human Rights
The Trevor Project
Transhealth
Whitman-Walker Institute

State organizations:

Ace and Aro Alliance of Central Ohio
Alaska Children's Trust
BAGLY (Boston Alliance of LGBTQ Youth)
Ca LGBTQ Health and Human Services Network
Children Now
Colorado Children's Campaign
Colors+
Equality California
Equitas Health
Florida Policy Institute
GenderNexus
Hawaii Children's Action Network Speaks!
Herman and Frieda L. Miller Foundation

Identity Health Clinic
New Mexico Voices for Children
Oasis Legal Services
Oklahoma Policy Institute
Omaha ForUs LGBTQ+ Center
Our Children Oregon
Rhode Island KIDS COUNT
Seattle's LGBTQ+ Center (formerly Gay City)
Silver State Equality-Nevada
Waves Ahead Puerto Rico
We Are Family
Western Montana LGBTQ+ Community Center

Local organizations:
Attic Youth Center
Bradbury-Sullivan LGBT Community Center
Center for Psychological Growth
Compass LGBTQ Community Center
Great Lakes Bay Pride
Institute for LGBT Health and Wellbeing
Lancaster LGBTQ+ Coalition
Latino Equality Alliance
LGBT Community Center of New Orleans
LGBTQ+ Spectrum of Findlay
Los Angeles LGBT Center
Mazzoni Center
North Shore Alliance of GLBTQ Youth, Inc. (NAGLY)
OutCenter Southwest Michigan
Pacific Pride Foundation
Pride Center of Terre Haute Inc.
Pride Community Center, Inc (Brazos Valley, Texas)
Pridelines
Proud Haven Inc
Rainbow Center

Rainbow Rose Center

Resource Center

San Diego Pride

Shoals Diversity Center

Southern Arizona AIDS Foundation (SAAF)

The Center: 7 Rivers LGBTQ Connection

The Equality Crew

the Montrose Center

The Spahr Center

Transinclusive Group

Uptown Gay and Lesbian Alliance (UGLA)

Youth OUTright WNC

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[34] *Bostock v. Clayton County*, 590 U.S. ___ (June 15, 2020), p. 1, available at https://www.supremecourt.gov/opinions/19pdf/17-1618_hfci.pdf

[35] See, for example, the National LGBTQ Task Force’s “Queer the Census” initiative https://www.thetaskforce.org/queerthecensus/ and the Leadership Conference Education Fund’s “Census Counts” campaign https://censuscounts.org/

[36] OMB Circular No. A-130, Managing Information as a Strategic Resource, Appx. II (rev. 2016).

[37] National Academies of Sciences, Engineering, and Medicine, “Measuring Sex, Gender Identity, and Sexual Orientation” (Washington: 2022), available at https://www.nap.edu/catalog/26424/measuring-sex-gender-identity-and-sexual- orientation.

[38] Ibid.