

March 16, 2023

Secretary Xavier Becerra
U.S. Department of Health and Human Services
Hubert H. Humphrey Building, Room 509F
200 Independence Avenue, SW
Washington, DC 20201

Re: Implementation of the Federal Evidence Agenda on LGBTQI+ Equity

Dear Secretary Becerra:

On behalf of the undersigned 12 organizations committed to advancing the health and wellbeing of lesbian, gay, bisexual, transgender, queer, intersex, and other sexual and gender minority (LGBTQI+) people in the United States, we write regarding the implementation of the Federal Evidence Agenda on LGBTQI+ Equity by the U.S. Department of Health and Human Services (HHS).

HHS has demonstrated a commitment to advancing the rights of LGBTQI+ communities and to adopting a data-driven approach to policymaking.¹ Since at least 2001, HHS has recognized the staggering health inequities that LGBTQI+ people face,² and in 2016 the Department developed a plan to advance LGBTQI+ health equity that included demographic data collection as a priority for both population-based surveys and program administration.³ Last year, HHS published a comprehensive list of strategies to improve demographic data collection for all projects and programs in its Strategic Plan for 2022-2026.⁴ Additionally, the Centers for Medicare & Medicaid Services (CMS) 2022-2032 Framework for Health Equity presents a commitment to improve standardized collection of information on beneficiary demographics and social determinants of health, including LGBTQI+ beneficiaries.⁵ We appreciate HHS' recognition of the critical role that data collection plays in conducting research, designing programs, crafting policies, and developing strategies to improve health equity for LGBTQI+ people.

We believe that the recent release of the Federal Evidence Agenda on LGBTQI+ Equity provides a crucial opportunity for HHS to enhance its collection of data on sexual orientation, gender identity, and variations in sex characteristics (SOGISC). Doing so will further HHS' goals of

¹ For example, see U.S. Department of Health and Human Services, "HHS Announces Prohibition on Sex Discrimination Includes Discrimination on the Basis of Sexual Orientation and Gender Identity," Press release, May 10, 2021, available at <https://www.hhs.gov/about/news/2021/05/10/hhs-announces-prohibition-sex-discriminationincludes-discrimination-basis-sexual-orientation-gender-identity.html>

² See Healthy People 2010: Companion Document for Lesbian, Gay, Bisexual, and Transgender (LGBT) Health, Gay and Lesbian Med. Assoc. (2001), https://www.glma.org/data/n_0001/resources/live/HealthyCompanionDoc3.pdf.

³ Advancing LGBT Health & Well-Being: 2016 Report, HHS LGBT Policy Coordinating Committee, U.S. Department of Health and Human Services. (2016), <https://www.hhs.gov/sites/default/files/2016-report-with-cover.pdf>.

⁴ See Objective 4.4: Improve Data Collection, HHS Strategic Plan FY 2022-2026, U.S. Department of Health and Human Services, <https://www.hhs.gov/about/strategic-plan/2022-2026/goal-4/objective-4-4/index.html>

⁵ Centers for Medicare and Medicaid Services, CMS Framework for Health Equity 2022-2032, <https://www.cms.gov/files/document/cms-framework-health-equity.pdf>.

expanding access, reducing disparities in health care, public health, and human services outcomes, and ensuring HHS programs reach LGBTQI+ and other underserved communities. As HHS creates its SOGISC Data Action Plan to implement the Federal Evidence Agenda on LGBTQI+ Equity as required by Executive Order 14075, we write to encourage the agency to adopt a series of recommendations that will support its aims to strengthen equitable access to health care and improve health conditions and outcomes for LGBTQI+ people.

Specifically, in order to achieve the goals of the Federal Evidence Agenda on LGBTQI+ Equity and answer guiding questions posed by its Learning Agenda, we urge HHS to expand collection of demographic SOGISC data on priority data collections and to support qualitative and community-based participatory research to better understand and address the health needs of particular subpopulations (Section III). Additionally, we urge HHS to invest resources and build infrastructure necessary to effectively implement its SOGISC Data Action Plan and the Federal Evidence Agenda on LGBTQI+ Equity at large (Section IV).

I. Background on Executive Order 14075

In June 2022, President Biden signed Executive Order 14075 on *Advancing Equality for Lesbian, Gay, Bisexual, Transgender, and Intersex Individuals* (EO 14075),⁶ which issued a range of important policy directives including those to expand and enhance data collection on sexual orientation, gender identity, and variations in sex characteristics (SOGISC). EO 14075 called for the Office of Management and Budget (OMB) to publish a report with recommendations for agencies on best practices for the collection of these data on Federal statistical surveys, which was finalized in January.⁷ This report, in addition to the comprehensive 2022 report from the National Academies of Sciences, Engineering, and Medicine is a key resource for recommendations on specific principles and measures for collecting SOGISC data.⁸

Crucially, EO 14075 also required the creation of an evidence agenda to coordinate a cross-government effort to promote and engage in inclusive and responsible data collection practices on SOGISC. In January 2023, the Subcommittee on Sexual Orientation, Gender Identity, and Variations in Sex Characteristics Subcommittee on Equitable Data of the National Science and Technology Council published the Federal Evidence Agenda on LGBTQI+ Equity (“Evidence Agenda”).⁹ This first-of-its-kind Evidence Agenda provides an overview of LGBTQI+ data needs, presents a Learning Agenda for federal agencies to use to advance LGBTQI+ equity, and offers guidelines for collecting SOGI data in administrative contexts. Next, EO 14075 directs federal agencies to submit SOGISC Data Action Plans detailing how they will use SOGISC data and implement the recommendations from the Evidence Agenda to advance equity for LGBTQI+ individuals.

⁶ The White House, “Executive Order on Advancing Equality for Lesbian, Gay, Bisexual, Transgender, Queer, and Intersex Individuals,” June 15, 2022, available at <https://www.whitehouse.gov/briefing-room/presidential-actions/2022/06/15/executive-order-on-advancing-equality-for-lesbian-gay-bisexual-transgender-queer-and-intersex-individuals/>.

⁷ <https://www.whitehouse.gov/wp-content/uploads/2023/01/SOGI-Best-Practices.pdf>

⁸ <https://www.nationalacademies.org/our-work/measuring-sex-gender-identity-and-sexual-orientation-for-the-national-institutes-of-health>

⁹ <https://www.whitehouse.gov/wp-content/uploads/2023/01/Federal-Evidence-Agenda-on-LGBTQI-Equity.pdf>

II. The Federal Evidence Agenda on LGBTQI+ Equity and Its Learning Agenda

The milestone Evidence Agenda serves as a roadmap for federal agencies as they create SOGISC Data Action Plans to help assess, improve, and monitor the health and well-being of LGBTQI+ people over time. Specifically, the Evidence Agenda instructs agencies to identify which surveys, surveillance systems, or program administrative data systems are most appropriate for collecting SOGISC data, as well as the ways in which smaller, more in-depth surveys, qualitative data collections, and community-based participatory research can improve LGBTQI+ equity.

To answer the core question “What additional evidence do we, as a Federal Government, need to more effectively advance equity for and improve the well-being of LGBTQI+ people?” the Evidence Agenda employs a Learning Agenda framework. The Learning Agenda offers a series of thirteen “overarching questions” that agencies should answer to assist the federal government’s efforts to further LGBTQI+ equity, each of which is paired with a set of detailed, empirically oriented “illustrative questions” to further guide agencies as they work to better support evidence-building (see [Appendix](#)).

The development of a comprehensive Data Action Plan by HHS is imperative to answer overarching questions in the “Health, Healthcare, and Access to Care,” section of the Learning Agenda, including:

- “To what extent can the Federal Government help protect and strengthen equitable access to high quality and affordable healthcare for LGBTQI+ people across the lifespan?” (Overarching Question #1)
- “To what extent can the Federal Government safeguard and improve health conditions and outcomes for LGBTQI+ people?” (Overarching Question #2)

Given the wide range of health and human services and data collections administered by HHS, the Department’s Data Action Plan should also address other overarching questions in the Learning Agenda, such as:

- “How can the Federal Government promote equitable access to and engagement in federal programs, benefits, and funding opportunities for eligible LGBTQI+ people?” (Overarching Question #7)
- “To what extent can the Federal Government understand LGBTQI+ children, youth, and families that touch the child welfare and foster care systems, improve any potential disparities in treatment while in care, and address potential disparate outcomes after leaving these systems?” (Overarching Question #10)
- “What can be done to reduce the disproportionately high rate of violent crime committed against LGBTQI+ people?” (Overarching Question #11)

In order to support HHS’ goal of advancing the Evidence Agenda and answering the questions of the Learning Agenda, we urge HHS to incorporate the below priority recommendations into its SOGISC Data Action Plan mandated under EO 14075. The following recommendations are organized according to the relevant operating divisions and agencies of HHS. Each recommendation is explicitly tied to the goals of the Learning Agenda: the way in which each data collection provides information to answer specific overarching questions and illustrative questions is indicated in parentheses. For reference, an [Appendix](#) is available. Because the OMB

report and the 2022 NASEM report provide detailed recommendations on specific principles and measures for collecting SOGISC data, the below recommendations are focused on particular data collections but do not recommend question designs, which may vary depending on the setting and details of each collection.

III. Recommendations to Advance the Goals of the Evidence Agenda and Learning Agenda

Enhancing the collection of SOGISC data on federally supported surveys, surveillance systems, and program administrative data systems is a key step to safeguard and advance the health and well-being of LGBTQI+ people. The recommendations offered below pertain to data collections in all of these contexts.

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 the report provides evidence to support adding SOGISC measures in each of these domains, accounting for differences related to the uses of data, identifiability of respondents, and the risk of data disclosure in each context.¹⁰ Notably, both the Evidence Agenda and NASEM report both have found that the federal government is especially well-positioned to expand and enhance demographic data collection on SOGISC in the context of federal surveys where recommendations for SOGI data measures and data collection methods exist, are well documented, and have been successful.¹¹

The Evidence Agenda also emphasizes that agencies would benefit from ensuring they have sufficient data on LGBTQI+ people in contexts in which they have a responsibility to implement programs, as well as to implement or enforce civil rights protections, such as those related to health care.¹² Integrating SOGISC demographic data collection into these datasets will enable effective examination of smaller underserved subpopulations – especially those living at the intersection of multiple marginalized identities – in ways that many existing surveys may not illuminate. Additionally, data collected before and after policy or programmatic change can help HHS evaluate the efficacy of those changes for LGBTQI+ communities. We recognize that there are challenges associated with collecting SOGISC data in these settings, but agree with the Evidence Agenda assertion that “these challenges can and should be overcome and should not be used as an excuse to avoid or delay SOGI data collection.”

As explained further in Section IV, we urge HHS to ensure that these recommendations are implemented in accordance with evidence-based best practices for including SOGISC measures in data collections and to engage in inclusive and responsible data collection practices that maintain statistical rigor, while safeguarding privacy, security, and civil rights. We note that the recommendations below identify many existing data collections that fail to include all or some

¹⁰ <https://www.nationalacademies.org/our-work/measuring-sex-gender-identity-and-sexual-orientation-for-the-national-institutes-of-health>

¹¹ <https://www.whitehouse.gov/wp-content/uploads/2023/01/Federal-Evidence-Agenda-on-LGBTQI-Equity.pdf> pg. 7 and <https://www.nationalacademies.org/our-work/measuring-sex-gender-identity-and-sexual-orientation-for-the-national-institutes-of-health>

¹² Ibid. at 12

SOGISC measures or collect these data in a way that is inconsistent across geographic regions or over time. HHS should remedy this by reviewing these existing data collections and comprehensively integrating evidence-based SOGISC measures that will enable the agency to gather new information and use existing data to improve health disparities, care quality, outcomes, and health risks among LGBTQI+ populations. Additionally, some illustrative questions in this Learning Agenda may be addressed best by integrating HHS-collected SOGI information with data collected in surveys or surveillance systems overseen by other agencies, such as the data collected on homelessness by the Department of Housing and Urban Development. This approach is in alignment with the Equitable Data Working Group’s recommendation to “catalyze existing Federal infrastructure to leverage underused data.”

a. Centers for Medicare & Medicaid Services

Collecting demographic data in federal health programs that serve the public is key to enable providers, plans, and programs to identify where disparities occur and collect actionable information to shape equitable policymaking. Information about the choice, affordability, and enrollment of LGBTQI+ people in healthcare coverage, as well as the quality of that insurance is extremely limited but essential to better comprehend barriers to access and how coverage for LGBTQI+ people may differ compared to other insured populations (1.1). Further, lack of data on LGBTQI+ people served by these programs obscures information on quality of care provided to LGBTQI+ persons overall.

To better understand these topics, the **Centers for Medicare and Medicaid Services should prioritize adding SOGI measures, as well as evaluate and add SC measures, on application forms for Medicare, Medicaid, and HealthCare.gov.** Enhancing SOGISC demographic data collection through these programmatic collections will help HHS understand the prevalence of LGBTQI+ people within these systems and provide information to examine barriers and disparities in the receipt, utilization, and quality of healthcare services among system participants (1.2). For instance, as CMS works to implement reporting of quality measures, CMS should incorporate demographic analysis, including SOGISC measures, to monitor differences and disparities among various populations. Such information will be especially helpful to understand the degree to which federal programs and policies enable access to gender-affirming care and improve health outcomes for transgender, nonbinary, and intersex individuals, and to identify barriers to necessary care as well as potentially harmful practices such as nonconsensual surgeries on intersex infants and children (1.3). Additionally, these data will shed light on disproportionate denials of health insurance claims and provide information to help prevent discriminatory denials for LGBTQI+ people (1.7), especially transgender people who continue to encounter insurers with plans that impose exclusions or restrictions on medically necessary procedures to treat gender dysphoria or affirm a patient’s gender (1.8).¹³ Data generated from these programs can and should be used to inform what services must be provided to meet the needs of LGBTQI+ populations, for example, through essential health benefits (EHB) and benchmark plans (1.2, 1.4).¹⁴ We already know through independent surveys and limited data

¹³ <https://www.americanprogress.org/article/advancing-health-care-nondiscrimination-protections-for-lgbtqi-communities/>

¹⁴ See NHeLP’s comments on EHB, <https://healthlaw.org/resource/nhelp-comments-on-essential-health-benefits-ehb-request-for-information-rfi/>.

collections that LGBTQI+ people disproportionately experience negative health and health care outcomes.¹⁵ Without actual information about LGBTQI+ individuals who access or attempt to access these programs, HHS cannot effectively and proactively address these issues at the individual, population, or program level (1.9).

CMS should also review how SOGISC data collection can be expanded in key data collections that support quality-of-care initiatives and patient-centered services for underserved and vulnerable communities. That includes incorporating SOGI measures, as well as evaluating and adding SC measures to **CMS quality improvement initiatives** like the **Consumer Assessment of Healthcare Providers & Systems** family of surveys and **standardized patient assessment data elements (SPADES)**.

b. Office for Civil Rights

Combating discrimination is essential to promote equitable access to health insurance coverage and care. We appreciate that HHS recognizes the importance of demographic data collection to understand population needs and advance health equity, as well as the fact that demographic data collection and civil rights enforcement are inextricably linked.¹⁶ Establishing demographic data as a function of civil rights monitoring across HHS will help to ensure and demonstrate compliance with the civil rights requirements of Section 1557 of the Patient Protection and Affordable Care Act¹⁷ and effective implementation of the *Bostock v. Clayton County* decision¹⁸, as well as Executive Order 13988.¹⁹ As HHS works to finalize its proposed rule on “Nondiscrimination in Health and Health Education Programs or Activities”,²⁰ **we renew our call for HHS’ Office for Civil Rights to adopt a basic demographic data requirement** and direct each sub-agency or program to set its own requirements and methods for data collection with a specific timeline for implementation. Such demographic data collection requirements should align with the demographic characteristics enumerated within the proposed rule,

¹⁵ Id.; and see <https://www.census.gov/library/stories/2021/11/census-bureau-survey-explores-sexual-orientation-and-gender-identity.html>

¹⁶ *Federal Register*, 87 (149) (2022): 47824-47920, available at <https://www.govinfo.gov/content/pkg/FR-2022-08-04/pdf/2022-16217.pdf>; HHS has incorporated demographic data collection into its 2022 Equity Action Plan, U.S. Dep’t of Health & Hum. Svcs., *Equity Action Plan* (Apr. 2022), available at <https://www.hhs.gov/sites/default/files/hhs-equity-action-plan.pdf>, and demographic data collection has long been a stated priority for its subagencies; see, e.g., Ctrs. for Medicare & Medicaid Svcs., *The CMS Equity Plan for Improving Quality in Medicare* (Sept. 2015), available at https://www.cms.gov/about-cms/agency-information/omh/omh_dwnld-cms_equityplanformedicare_090615.pdf; Ctrs. for Medicare & Medicaid Svcs., *CMS Framework for Health Equity 2022-2032* (Apr. 2022); available at <https://www.cms.gov/files/document/cms-framework-health-equity.pdf>; Ctrs. for Medicare & Medicaid Svcs., *CMS Strategic Plan, Pillar: Health Equity* (Aug. 2022), available at https://www.cms.gov/sites/default/files/2022-04/Health%20Equity%20Pillar%20Fact%20Sheet_1.pdf

¹⁷ *Federal Register*, 87 (149) (2022): 47824-47920, available at <https://www.govinfo.gov/content/pkg/FR-2022-08-04/pdf/2022-16217.pdf>

¹⁸ *Bostock v. Clayton County*, 590 U.S. ____ (June 15, 2020), p. 1, available at https://www.supremecourt.gov/opinions/19pdf/17-1618_hfci.pdf

¹⁹ <https://www.whitehouse.gov/briefing-room/presidential-actions/2021/01/20/executive-order-preventing-and-combating-discrimination-on-basis-of-gender-identity-or-sexual-orientation/>

²⁰ *Federal Register*, 87 (149) (2022): 47824-47920, available at <https://www.govinfo.gov/content/pkg/FR-2022-08-04/pdf/2022-16217.pdf>

including: race, ethnicity, language, disability, age, sex, sexual orientation, gender identity, pregnancy status, and variations in sex characteristics.

Adopting this baseline demographic data requirement will help HHS better comprehend the ways in which its federal programs and policies affect quality of healthcare services (1.2), provide insight into the role that local, state, and federal laws play in restricting or enhancing equitable access to healthcare for LGBTQI+ individuals and families (1.5), and understand the extent to which recent efforts to prohibit and criminalize the provision and receipt of healthcare—including reproductive care and gender-affirming care—affect health outcomes for LGBTQI+ people (1.6), especially for transgender people, people who can become pregnant, people of color, and people with disabilities (1.6). Similarly, these data may shed light on potential civil rights and privacy violations in medical and informed consent practices toward infants and children with intersex variations, including non-consensual surgeries increasingly promoted by some state laws (1.7). These data will also facilitate analysis of disaggregated data and enable targeted enforcement of other forms of civil rights violations, including harassment and discriminatory provision of delayed or substandard care, that we already know occur in each of these settings.

c. Centers for Disease Control and Prevention

The Centers for Disease Control and Prevention (CDC) should add questions that allow for the identification of LGBTQI+ people to the core component of the **Behavioral Risk Factor Surveillance System** (BRFSS), which collects health and risk behavior data. The large sample size of the BRFSS system makes it the most valuable federal health surveillance system, offering the largest source of population-based sexual orientation data, the only source of population-based gender identity data, and the only source of these data available by state.²¹ These data enable richer information on the outcomes of particular LGBTQ+ subpopulations—such as transgender people or LGBTQ people of color—especially when aggregated across years.²² In 2020, 32 states and Guam used the sexual orientation and gender identity optional question module, but these measures are not part of the standardized demographic core questionnaire that every state uses each year, meaning that this extremely valuable data source is currently unable to provide full U.S. data.²³ BRFSS currently lacks a measure that can identify intersex populations, although the largest U.S. survey of intersex adults to date found striking health disparities using questions derived from the BRFSS survey.²⁴

Adding SOGI questions, as well as evaluating and adding a measure of variations in sex characteristics, to the standardized demographic core questionnaire would enhance consistency and improve data validity and the ability to make national-level inferences from this key

²¹ Centers for Disease Control and Prevention, “Behavioral Risk Factor Surveillance System About BRFSS,” available at <https://www.cdc.gov/brfss/about/index.htm> (last accessed September 2022)

²² Centers for Disease Control and Prevention, “Behavioral Risk Factor Surveillance System About BRFSS,” available at <https://www.cdc.gov/brfss/about/index.htm> (last accessed September 2022)

²³ Centers for Disease Control and Prevention, “Behavioral Risk Factor Surveillance System – Questionnaires 2020 Modules by State by Data Set & Weight” available at <https://www.cdc.gov/brfss/questionnaires/modules/state2020.htm> (last accessed September 2022).

²⁴ Rosenwohl-Mack A, et al. A national study on the physical and mental health of intersex adults in the U.S. *PLoS One*. 2020 Oct 9;15(10):e0240088. doi: 10.1371/journal.pone.0240088.

dataset.²⁵ By collecting data on health-related risk behaviors linked to chronic and infectious diseases, as well as injuries, BRFSS serves as a powerful tool to target and promote healthy behaviors and reduce occurrence and disparities in preventable injury, illness, and death (2.3) at a scale that allows us to understand the extent to which these dimensions of health vary by geographic region (2.8) and different demographic characteristics (2.9). Having standardized SOGISC questions and response options is important so that researchers can pool data from many states and have the power to look at racial and ethnic differences, age cohort differences, sex differences, geographical variation, and other important intersectional issues.

CDC should also expand SOGISC measurement in youth-focused health surveys and data collections, including by testing and adding a nonbinary-inclusive measure of gender identity and evaluating and adding questions about intersex variations to the **both the national and standard Youth Risk Behavior Surveillance System (YRBSS)** questionnaires in order to assess what progress has been made to achieve national, state, and local health objectives for LGBTQI+ youth (2.10) and mitigate disparities to reduce negative mental health outcomes among LGBTQI+ youth (1.10). YRBSS data are used to monitor health behaviors and experiences that contribute to the leading causes of death and disability among young people,²⁶ and have revealed disturbing disparities among LGBQ+ youth with respect to substance use and misuse, negative mental health outcomes, and experiences of violence.²⁷ While evidence shows that nonbinary and intersex students are at heightened risk of experiencing negative mental health outcomes,²⁸ a lack of YRBSS data poses a barrier to deepening our understanding of those experiences and to crafting effective policy solutions. Improving SOGISC data collection on YRBSS is especially critical at a time when LGBTQI+ youth—especially transgender and intersex youth - are being targeted by a wave of discriminatory attacks.²⁹

Similarly, the National Centers for Health Statistics (NCHS) should initiate and expand SOGISC data collection throughout its population and provider surveys, including but not limited to the **National Health Interview Survey (NHIS)**. NHIS already collects demographic data on sexual orientation, offering insight into the chronic health conditions, disability status, health insurance, health care access and use, and health-related behaviors of LGB populations.³⁰ NCHS should make permanent measures of gender identity, as well as evaluate and add questions that allow for the identification of people with intersex variations on the NHIS. Doing so would enable HHS to generate nationally representative data on LGBTQI+ populations to monitor trends in illness and disability, identify barriers to accessing and using health care services, and assess progress to

²⁵ National LGBT Cancer Network, “Advancing Sexual Orientation/Gender Identity (SOGI) Measures in the Behavioral Risk Factor Surveillance System (BRFSS)”, available at <https://cancer-network.org/wp-content/uploads/2021/04/BRFSS-Justification-Sheet-April-2021-version-2-3.pdf> (last accessed September 2022)

²⁶ Centers for Disease Control and Prevention, “Youth Risk Behavior Surveillance System (YRBSS)” available at <https://www.cdc.gov/healthyyouth/data/yrbs/index.htm> (last accessed September 2022)

²⁷ https://www.cdc.gov/healthyyouth/data/yrbs/pdf/YRBS_Data-Summary-Trends_Report2023_508.pdf

²⁸ <https://www.thetrevorproject.org/survey-2022/>; <https://www.thetrevorproject.org/wp-content/uploads/2021/12/Intersex-Youth-Mental-Health-Report.pdf>

²⁹ <https://www.americanprogress.org/article/state-attacks-against-lgbtqi-rights/>

³⁰ <https://www.cdc.gov/nchs/data/nhis/Sample-Questionnaire-Brochure.pdf>

achieving national health objectives (2.3), as well as to engage in epidemiologic and policy analysis and evaluation of federal health programs.³¹

CDC should also add SOGI measures to—and evaluate and add SC measures for—the **National Electronic Disease Surveillance System Base System (NBS) and to its case report form guidance for reportable diseases such as mpox and HIV**. The emergence of the mpox virus has underscored the importance of the NBS and the need to ensure it includes SOGISC measures that enable it to better serve LGBTQI+ populations. Incorporating these measures into the NBS will help to ensure that LGBTQI+ populations are included in disease reporting and improve the ability of governments to prepare for, respond to, and recover from public health emergencies (2.1) and to assess the effectiveness of efforts to protect LGBTQI+ people from infectious disease and prevent non-communicable disease through development and equitable delivery of treatments, vaccines, and other services (2.2). To this end, CDC’s **Data Modernization Initiative** must also incorporate specific investments in infrastructure that can support the collection, exchange, analysis, and reporting of SOGISC data.

LGBTQI+ communities continue to experience elevated rates of violence and victimization, including family violence, intimate partner violence, and bias-motivated violence.³² Research also shows that LGBTQ people are at disproportionate risk of suicidal ideation, planning, and attempts.³³ We urge HHS to expand the use of SOGISC measures in CDC Injury Center surveys and data collections, including by implementing policies and procedures to **require the National Violent Death Reporting System (NVDRS)** to collect data that allows for the identification of LGBTQI+ people. 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.³⁴ Implementing policies and procedures to add SOGISC measures to the NVDRS is essential in order to inform interventions to reduce the disproportionately high rate of violent crime committed against LGBTQI+ people and prevent the occurrence of violent deaths in the United States (11.1, 11.3). Such interventions are crucial for all LGBTQI+ people, but especially LGBTQI+ youth (1.10) who are at increased risk for suicide due to mistreatment and stigmatization,³⁵ as well as transgender women—especially transgender women of color—who continue to face epidemic levels of violence.³⁶ Offering technical assistance support on implementation at the local level and partnering with organizations developing and testing methods for SOGI mortality data collection with death investigators in the field³⁷ will be crucial to furthering progress.

³¹ <https://www.cms.gov/about-cms/agency-information/omh/resource-center/hcps-and-researchers/data-tools/sgm-clearinghouse/nhis>

³² <https://www.nationalacademies.org/our-work/understanding-the-status-and-well-being-of-sexual-and-gender-diverse-populations>

³³ <https://williamsinstitute.law.ucla.edu/press/suicide-prevention-media-alert/>

³⁴ Centers for Disease Control and Prevention, National Violent Death Reporting System (NVDRS)” available at <https://www.cdc.gov/violenceprevention/datasources/nvdrs/index.html> (last accessed September 2022)

³⁵ The Trevor Project, “2022 National Survey on LGBTQ Youth Mental Health” available at <https://www.thetrevorproject.org/survey-2022/> (last accessed September 2022)

³⁶ 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> (last accessed September 2022)

³⁷ <https://www.lgbtmortality.com/about-the-project>

d. Office of the National Coordinator for Health Information Technology

Improving SOGISC data collection in health IT interoperability systems is essential to support informed decision-making and the provision of person-centered care for LGBTQI+ and other underserved communities. The HHS Office of the National Coordinator for Health Information Technology (ONC) United States Core Data for Interoperability (USCDI) is a standardized set of health data classes and constituent data elements for nationwide interoperable health information exchange that comprises a core set of data needed to support patient care and facilitate patient access using health IT.³⁸ HHS has identified a need to enhance the accuracy and inclusiveness of SOGI data on LGBTQI+ populations by assessing how to incorporate newly adopted and updated recommendations on appropriate terminology and data standards into the USCDI and CMS programs.³⁹ We urge HHS to ensure the finalized **USCDI version 4 includes improved sex, sexual orientation, and gender identity data elements and adds a standalone data element for variations in sex characteristics**.⁴⁰ Specifically, we strongly support the ONC adopting data elements designed in alignment with recommendations submitted by the Health Level Seven International (HL7) Gender Harmony Project.⁴¹ Doing so is critical to better standardize the sharing of electronic health data, foster interoperability in health information exchange, facilitate monitoring of LGBTQI+ population disparities in public health surveillance, improve integration of care across providers, support cultural competency, and address public health interoperability needs related to reporting, investigation, and emergency response (2.1, 2.11).

e. Administration for Children and Families

Existing evidence reveals that LGBTQI+ youth are overrepresented in the foster care system, have worse experiences in the system than their non-LGBTQI+ peers, and are at heightened risk for poor outcomes once exiting the system.⁴² For these reasons, we urge the Administration for Children and Families to improve the collection of data in the **Adoption and Foster Care Analysis and Reporting System (AFCARS)** by including voluntary SOGI and gender expression questions for youth over 14 and adoptive and foster parents and guardians. ACF should also invest resources in additional research to evaluate adding questions on intersex status to better understand the experiences and outcomes of intersex youth in contact with the foster care system. Enhancing SOGISC data collection in AFCARS will help researchers, policymakers, and advocates better understand the experiences and outcomes of LGBTQI+ youth in contact with the foster care system—especially transgender or nonbinary foster youth,

³⁸ <https://www.cms.gov/files/document/path-forwardhe-data-paper.pdf>

³⁹ Ibid.

⁴⁰ See <https://www.healthit.gov/isa/uscdi-data/variation-sex-characteristics>.

⁴¹ HL7 Gender Harmony Project, “Official Response to USCDI v3,” available at https://www.healthit.gov/isa/sites/isa/files/2022-04/HL7_GH_uscdi_response_03142022.pdf (last accessed May 2022).

⁴² Wilson, B. D. M., Cooper, K., Kastanis, A., Nezhad, S. (2014). Sexual and Gender Minority Youth in Foster Care: Assessing Disproportionality and Disparities in Los Angeles. The Williams Institute. <https://williamsinstitute.law.ucla.edu/publications/sgm-youth-la-foster-care/>; U.S. Government Accountability Office. (2022). Foster Care: Further Assistance from HHS Would be Helpful in Supporting Youth’s LGBTQ+ Identities and Religious Beliefs (Report No. GAO-22-104688). <https://www.gao.gov/assets/gao-22-104688.pdf>

LGBTQI+ youth living in rural areas, and LGBTQI+ youth of color—and how they may differ from their non-LGBTQI+ peers (10.1, 10.2, 10.3), as well as what programs and services can improve outcomes for LGBTQI+ youth (10.4).

f. Administration for Community Living

Evidence shows that LGBTQ older adults face acute levels of economic insecurity, social isolation, and discrimination, including but not limited to accessing critical aging services and supports.⁴³ The Administration for Community Living (ACL) should also continue to build on existing efforts to enhance SOGISC data collection on the **National Survey of Older Americans Act Participants** (NSOAAP), an annual national survey to assess the effectiveness of programs on aging funded by Title III of the Older Americans Act (OAA), which is the primary vehicle for delivering social support and nutrition programs to older adults.⁴⁴ Doing so will improve our understanding of the extent to which LGBTQI+ older adults experience disparate access to benefits and services provided through Title III (7.9).

g. Additional programmatic and clinical data collections

We note that there are a number of other critical surveys and other data collections that are overseen by other operating divisions across HHS, including the Indian Health Service (IHS), the Substance Abuse and Mental Health Services Administration (SAMHSA), the Health Resources and Services Administration (HRSA), and the National Institutes of Health (NIH) that operate grant programs, provide direct care and services, conduct research, and develop policies that are critical to the health and well-being of LGBTQI+ people, particularly, in the case of IHS, of Two-Spirit people. We strongly recommend that the HHS SOGI Data Action Plan identify specific opportunities for these divisions to support clinicians, program administrators, survey administrators, and other staff and contractors to expand and improve the data they collect through programmatic data collections such as HRSA's Ryan White Program client-level data report form,⁴⁵ surveys such as SAMHSA's National Survey of Drug Use and Health (NSDUH), patient-level data collections such as the IHS Resource and Patient Management System (RPMS) and the NIH Clinical Center electronic medical record (EMR), and both intramural and extramural research studies at NIH.

Given evidence of existing disparities, HHS would also benefit from ensuring it has sufficient data on LGBTQI+ people in contexts in which it has a responsibility to implement programs, especially those aimed at addressing housing insecurity and experiences of homelessness, particularly among children and families. A number of these human services programs would benefit from more information on program outcomes and the unique needs of LGBTQI+ families, as well as documentation of barriers to access related to names and gender markers. Such programs include the **Temporary Assistance for Needy Families (TANF)** program and

⁴³ <https://www.americanprogress.org/article/trump-administration-rolling-back-data-collection-lgbt-older-adults/>

⁴⁴ <https://www.cms.gov/about-cms/agency-information/omh/resource-center/hcps-and-researchers/data-tools/sgm-clearinghouse/nsoaap> and <https://aoasurvey.org/>

⁴⁵ The Ryan White Program currently collects gender identity data but does not do so in a manner recommended by either NASEM or OMB; it also does not collect demographic data on sexual orientation. <https://ryanwhite.hrsa.gov/sites/default/files/ryanwhite/data/rwhap-annual-client-level-data-report-2021.pdf>

the **Family Violence Prevention and Services Grant Program**. A critical first step might be to request information on these challenges from participating jurisdictions, including challenges to SOGISC data collection, and to develop guidance and technical assistance based on this feedback. Improving collection of data in these settings will support HHS’ goal of promoting equitable access to and engagement in federal programs for eligible LGBTQI+ people (7.7) and shed light on how discrimination or lack of cultural competency in the provision of human services impact LGBTQI+ people’s ability to apply for benefits (7.5).

IV. Implementation and necessary infrastructure

We support enhancing data collection on LGBTQI+ populations through these recommendations in a way that maintains statistical rigor, as well as robust privacy, confidentiality, and security standards. 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.⁴⁶ 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.

The federal government is especially well-positioned to expand and enhance demographic data collection on SOGISC in 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.⁴⁷ While evidence shows SOGISC questions are not especially sensitive,⁴⁸ in certain administrative and programmatic settings, there may be heightened risk of disclosure or misuse, especially in situations where collection is mandatory, is used as personally identifiable information (PII), or both. As noted in the Evidence Agenda, “Disclosure risks and sensitivity have sometimes been used as reasons to not collect [SOGISC] data. However, these concerns should not be used as a default barrier to data collection. It is possible to collect better [SOGISC] data and information to inform policy while balancing these protections.”⁴⁹ We strongly support HHS assessing and implementing practices needed to ensure confidentiality, privacy, and protection from improper use or disclosure in these collections. We urge HHS to take care to ensure adequate policies to protect data are in place, such as those outlined in Chapter 3 of the Evidence Agenda.

⁴⁶ OMB Circular No. A-130, Managing Information as a Strategic Resource, Appx. II (rev. 2016).

⁴⁷ 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>

⁴⁸ Ibid.

⁴⁹ <https://www.whitehouse.gov/wp-content/uploads/2023/01/Federal-Evidence-Agenda-on-LGBTQI-Equity.pdf> pg.

Further, it is essential that HHS secure adequate staffing and funding to effectively operationalize and implement its SOGISC Data Action Plan and the recommendations of the Evidence Agenda. We urge HHS to include in its annual budget submission a request for necessary funding increases to support implementation of its SOGISC Data Action Plan in compliance with EO 14075. In addition to staffing investments, appropriations requests should also factor in costs associated with research and testing of measures, strategic planning, technical assistance and training, cross-department and cross-agency collaboration, and developing interoperability capabilities and other infrastructure to support the effective collection and reporting of SOGISC demographic data while safeguarding privacy, security, and civil rights. To promote transparency and accountability, we also request that HHS provide regular updates on reporting of progress and additional planning to advance data equity for LGBTQI+ communities.

V. Conclusion

Our organizations are dedicated to supporting HHS' development of its SOGISC Data Action Plan and implementation of the Federal Evidence Agenda on LGBTQI+ Equity, 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.

Thank you for your consideration. Please do not hesitate to contact Kellan Baker, KBaker@whitman-walker.org, if you need any additional information.

Sincerely,

CA LGBTQ Health and Human Services Network
Center for American Progress
The Center for LGBTQ Health Equity, Chase Brexton Health Care
Fenway Health
GLMA: Health Professionals Advancing LGBTQ+ Equality
GLSEN
Howard Brown Health
interACT: Advocates for Intersex Youth
Movement Advancement Project
National Center for Lesbian Rights
National Health Law Program
Whitman Walker Institute

Appendix

1. Overarching Question #1: To what extent can the Federal Government protect and strengthen equitable access to high-quality and affordable healthcare for LGBTQI+ people across the lifespan?

1. To what extent do federal policies and programs affect choice, affordability, and enrollment among LGBTQI+ individuals and families in high-quality healthcare coverage?
2. To what extent do federal programs and policies improve quality of healthcare services for LGBTQI+ people?
3. To what extent do federal programs and policies support and promote gender-affirming care and improved health outcomes for transgender, intersex, and non-binary individuals?
4. To what extent do federal programs and policies strengthen and expand access to mental and behavioral health services, primary care, and preventive services for LGBTQI+ people?
5. What role do local, state, and federal laws play in restricting or enhancing equitable access to quality and affordable healthcare for LGBTQI+ individuals and families?
6. To what extent do restrictions and criminalization of healthcare receipt affect health outcomes for LGBTQI+ people?
7. To what extent do LGBTQI+ people experience disparate rates of access to health insurance coverage? Does coverage for LGBTQI+ people differ compared to other insured people?
8. To what extent do LGBTQI+ people face disproportionate denials of health insurance claims? To what extent do these denials impact health outcomes for this population?
9. Which federal programs and policies advance equitable access of culturally and clinically competent health care to various vulnerable subpopulations, such as LGBTQI+ older adults or LGBTQI+ youth engaged in the foster care system?
10. How can disparities experienced by LGBTQI+ youth be mitigated to reduce suicide risk among various subgroups?

2. Overarching Question #2: To what extent can the Federal Government safeguard and improve health conditions and outcomes for LGBTQI+ people?

1. To what extent are improvements to federal capabilities needed to predict, prepare for, respond to, and recover from public health emergencies and threats to LGBTQI+ people in the nation and across the globe?
2. How effective are federal programs and policies at protecting LGBTQI+ people from infectious disease and preventing non-communicable disease through

development and equitable delivery of effective, innovative, and readily available treatments, therapeutics, medical devices, and vaccines?

3. How do federal policies and programs enhance promotion of healthy behaviors and wellness among LGBTQI+ people to reduce occurrence of and disparities in preventable injury, illness, and death?
4. How effective are federal programs and policies at mitigating the impacts of occupational and environmental factors, including climate change, on health outcomes among LGBTQI+ people?
5. What training do medical providers receive in cultural competency and health care for LGBTQI+ people? To what extent does this training affect care and health outcomes for LGBTQI+ patients?
6. What barriers do LGBTQI+ minors and LGBTQI+ adults with disabilities face in accessing health services that require participation from guardians?
7. To what extent do elder LGBTQI+ people experience differential treatment and services in long term care settings? What effect, if any, do these disparities in treatment and services have on their well-being?
8. To what extent do health outcomes for LGBTQI+ people vary by geographic region?
9. To what extent do health outcomes for LGBTQI+ people vary by demographic characteristics, including, but not limited to, race and ethnicity, age, and whether the individual has a disability?
10. What progress has been made in achieving national, state, and local health objectives for LGBTQI+ youth?
11. What improvements would strengthen public health surveillance, epidemiology, and laboratory capacity to understand and equitably address diseases and conditions that impact LGBTQI+ people?

7. Overarching Question # 7: How can the Federal Government promote equitable access to and engagement in federal programs, benefits, and funding opportunities for eligible LGBTQI+ people?

1. What are the rates of participation for LGBTQI+ people in federal benefits programs, and how do these rates compare to their non-LGBTQI+ peers? Do these participation rates differ by geographic units such as states, regions, or the urban/rural divide?
2. What social, economic, and programmatic factors can account for observed differences between LGBTQI+ people and their non-LGBTQI+ peers in observed rates of participation in federal programs, benefits, and funding opportunities? In observed engagement rates?
3. How well do LGBTQI+ populations understand the federal programs and benefits they are eligible for and how to access them? How are understanding levels impacted by factors such as low literacy and language access needs?

4. To what extent do award rates differ for LGBTQI+ applicants to federal funding opportunities, holding other characteristics constant? Do these rates differ for subgroups of the LGBTQI+ population?
5. How do discrimination and lack of cultural competency in healthcare and human services affect LGBTQI+ people's ability to apply for benefits?
6. How do federal agencies communicate to and tailor communications about their programs and benefits to LGBTQI+ people?
7. To what extent does having identity documents that do not reflect an individual's affirmed name or gender affect access to benefits and programs? To what extent can the Federal Government mitigate barriers related to acquiring or updating identity documents?
8. To what extent do LGBTQI+ people experience challenges in receiving benefits compared to their non-LGBTQI+ peers?
9. To what extent do LGBTQI+ older adults experience disparate access to benefits and services?
10. To what extent do LGBTQI+ people report discrimination or mistreatment when accessing benefits? Do rates of discrimination or mistreatment experienced by LGBTQI+ people differ from rates experienced by non-LGBTQI+ people? Do rates of discrimination or mistreatment experienced by LGBTQI+ people of color differ from rates experienced by other LGBTQI+ people or from non-LGBTQI+ people of color?
11. To what extent do LGBTQI+ minors or LGBTQI+ people with disabilities face barriers in accessing federal programs and benefits that require participation from guardians?
12. To what extent does collection and use of SOGI data affect the customer experiences of LGBTQI+ populations when accessing federal services and programs?
13. What is the likelihood among LGBTQI+ populations to avoid seeking services or programmatic access due to concerns about being asked questions about sexual orientation or gender identity or due to other concerns around processes?

10. Overarching Question #10: To what extent can the Federal Government understand LGBTQI+ children, youth, and families that touch the child welfare and foster care systems, improve any potential disparities in treatment while in care, and address potential disparate outcomes after leaving these systems?

1. To what extent do the experiences of LGBTQI+ youth that led them to be in contact with the foster care system differ from their non-LGBTQI+ peers?
2. To what extent do the relationships between the experiences of LGBTQI+ foster youth (e.g., number of placements, placement in a group home, kinship placements) and their outcomes differ from those of their non-LGBTQI+ peers?
3. To what extent are there disparities in experiences and outcomes of specific subgroups of LGBTQI+ foster youth, including transgender or non-binary foster youth, LGBTQI+ youth living in rural areas, or LGBTQI+ youth of color, during and after their time in care?

4. What programs, services, or other approaches are effective in improving outcomes for LGBTQI+ youth who come into contact with the child welfare system?
5. To what extent do LGBTQI+ families that come into contact with the child welfare system experience differential treatment and disparate outcomes?
6. To what extent do rates of removal differ for LGBTQI+ parents? Do these rates differ amongst specific subgroups of LGBTQI+ parents (e.g., by race or ethnicity or for individuals with disabilities)? What, if anything, contributes to these rates of removal?

11. Overarching Question # 11: What can be done to reduce the disproportionately high rate of violent crime committed against LGBTQI+ people?

1. To what extent do LGBTQI+ people experience a higher rate of intimate partner violence or domestic violence compared to the general population?
2. To what extent do LGBTQI+ people experience bias-motivated hate crimes?
3. What have been effective or promising practices that prevent or interrupt violent crime targeting LGBTQI+ people?
4. To what extent do LGBTQI+ people utilize crime victim service assistance compared to the general population?
5. To what extent do LGBTQI+ students experience bullying compared to the general student population?
6. How effective are bullying interventions for LGBTQI+ youth compared to non-LGBTQI+ youth?