

June 21, 2022

TO: The Honorable Xavier Becerra, Secretary of Health and Human Services

CC: Admiral Rachel L. Levine, MD, Assistant Secretary for Health;  
January Contreras, JD, ACF Administrator;  
Alison Barkoff, JD, ACL Administrator;  
Robert Otto Valdez, PhD, AHRQ Administrator;  
Ellen Montz, PhD, Deputy Administrator and Director of the Center for Consumer Information and Insurance Oversight;  
Rochelle P. Walensky, MD, Director of the Centers for Disease Control and Prevention;  
Derrick Harkins, MDiv, Center for Faith-Based and Neighborhood Partnerships Administrator;  
Chiquita Brooks-LaSure, MPP, Administrator for the Centers for Medicare and Medicaid Services;  
Lisa Pino, JD, Director, Office for Civil Rights, HHS;  
Robert M. Califf, MD, FDA Administrator  
Benjamin Sommers, MD, PhD, Senior Official Performing the Duties of the Assistant Secretary for Planning and Evaluation, Deputy Assistant Secretary, Office of Health Policy;  
Carole Johnson, MA, HRSA Administrator;  
Elizabeth Fowler, BS, IHS Administrator;  
LaShawn McIver, MD, Director of the Office of Minority Health;  
Lawrence A. Tabak, DDS, PhD, NIH Administrator;  
Micky Tripathi, PhD, ONC Administrator;  
Miriam E. Delphin-Rittmon, PhD, SAMHSA Administrator;  
Vice Admiral Vivek Murthy, MD, U.S. Surgeon General,

Re: Expanding and enhancing data collection on LGBTQI+ communities

Dear Secretary Becerra:

On behalf of the undersigned 42 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 in response to President Biden's June 15 Executive Order on Advancing Equality for Lesbian, Gay, Bisexual, Transgender, Queer, and Intersex Individuals<sup>1</sup> and the recent release of the National Academies of Sciences, Engineering, and Medicine's (NASEM) report *Measuring Sex, Gender Identity, and Sexual Orientation*.<sup>2</sup> The milestone NASEM report presents guiding principles and best practices for collecting data on sex, sexual orientation, gender identity, and variations in sex characteristics, which are essential to identify and address the specific needs of LGBTQI+ populations. We are thrilled to see sexual orientation, gender identity, and sex characteristics inclusive data collection in President Biden's Executive Order. Data collection is a

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<sup>1</sup> Executive Office of the President, "Advancing Equality for Lesbian, Gay, Bisexual, Transgender, Queer, and Intersex Individuals," *Federal Register* 87 (118) (2022): 37189-95, available at <https://www.govinfo.gov/content/pkg/FR-2022-06-21/pdf/2022-13391.pdf>

<sup>2</sup> 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>.

critical goal for this Administration as well as for us, and we are so appreciative of the opportunity to work in partnership with you.

The U.S. Department of Health and Human Services (HHS) has demonstrated a commitment to advancing the rights of LGBTQI+ communities and to adopting a data-driven approach to policymaking.<sup>3</sup> Since at least 2001, HHS has recognized the staggering health inequities that LGBTQI+ people face,<sup>4</sup> 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.<sup>5</sup> Just recently, HHS published a comprehensive list of strategies to improve demographic data collection for all projects and programs in its Strategic Plan for 2022-2026.<sup>6</sup> The Centers for Medicare & Medicaid Services (CMS) put expanded demographic data collection front and center in its 2022-2032 Framework for Health Equity. Priority 1 of CMS's Framework outlines a commitment to improve standardized collection of information on beneficiaries' "race, ethnicity, language, gender identity, sex, sexual orientation, disability status, and social determinants of health."<sup>7</sup>

We now write to encourage HHS to continue building on its historic work by adopting the NASEM report's recommendations. Specifically, we respectfully request that HHS take necessary action to 1) support the addition of recommended measures of sexual orientation, gender identity, and variations in sex characteristics to priority HHS data collection mechanisms and 2) invest in future research to continue to develop, test, and improve measures of sexual orientation, gender identity, and sex characteristics.

Implementing and continuously improving these measures is essential to capture a more comprehensive, accurate, and data-driven understanding of the disparities and challenges that LGBTQI+ communities face with regard to their health, well-being, and opportunities, and to develop evidence-based policy interventions that advance health and equity. Expanding and enhancing data collection on LGBTQI+ communities is also critical to fulfill directives set out by Executive Order 13985,<sup>8</sup> which directs federal agencies to promote equity for LGBTQI+ and other underserved communities through various actions, including but not limited to increasing data collection efforts.

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<sup>3</sup> 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-discrimination-includes-discrimination-basis-sexual-orientation-gender-identity.html>.

<sup>4</sup> See Healthy People 2010: Companion Document for Lesbian, Gay, Bisexual, and Transgender (LGBT) Health, Gay and Lesbian Med. Assoc. (2001), [https://www.gлма.org/\\_data/n\\_0001/resources/live/HealthyCompanionDoc3.pdf](https://www.gлма.org/_data/n_0001/resources/live/HealthyCompanionDoc3.pdf).

<sup>5</sup> 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>.

<sup>6</sup> See Objective 4.4: Improve Data Collection, HHS Strategic Plan FY 2022-2026, U.S. Department of Health and Human Services, <https://healthpiguay.substack.com/p/the-scheduling-conundrum?s=r>.

<sup>7</sup> Centers for Medicare and Medicaid Services, CMS Framework for Health Equity 2022-2032, <https://www.cms.gov/files/document/cms-framework-health-equity.pdf>.

<sup>8</sup> Executive Office of the President, "Advancing Racial Equity and Support for Underserved Communities Through the Federal Government," *Federal Register* 86 (14) (2021): 7009-7013, available at <https://www.govinfo.gov/content/pkg/FR-2021-01-25/pdf/2021-01753.pdf>

As such, we urge HHS to take swift and meaningful action to adopt the NASEM report's recommendations and to begin collecting these important data as soon as possible.

## I. The need to collect quality data on LGBTQI+ populations

Existing research reveals that LGBTQI+ people encounter significant barriers to accessing affordable, quality health care and insurance, as well as disparate outcomes related to physical, mental, and behavioral health.<sup>9</sup> Importantly, the health of LGBTQI+ communities is severely impacted by discrimination, stigma, prejudice, as well as other social determinants of health.<sup>10</sup> For transgender individuals,<sup>11</sup> LGBTQI+ people of color,<sup>12</sup> and LGBTQI+ people with disabilities,<sup>13</sup> obstacles to care and disparate health outcomes are even more pronounced. Health and social disparities affect LGBTQI+ children, youth, families, and older adults, including in the child welfare system and in accessing necessary services and supports across the lifespan.<sup>14</sup>

Lack of routine data collection on sexual orientation, gender identity, and variations in sex characteristics remains a significant barrier for policymakers, researchers, service providers, and advocates who want to more deeply understand these disparities and improve the wellbeing of LGBTQI+ communities. Currently, only a limited number of HHS-supported surveys collect data on sexual orientation and gender identity, and none ask questions that allow for the identification of people with intersex traits. HHS operating divisions that provide direct services to beneficiaries, such as CMS, also often do not require collection of information on the sexual orientation, gender identity, or variations in sex characteristics of their program participants even where other demographic data are collected. These gaps significantly restrict our ability to better understand and address the health and social challenges that LGBTQI+ people and their families face.<sup>15,16</sup> Improving data collection on sexual orientation, gender identity, and variations in sex characteristics will help researchers characterize the experiences and outcomes of LGBTQI+ people; health care and human services

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<sup>9</sup> National Academies of Sciences, Engineering, and Medicine, "Understanding the Wellbeing of LGBTQI+ Populations" (Washington: 2020), available at <https://www.nap.edu/read/25877/chapter/1>

<sup>10</sup> Ibid.

<sup>11</sup> Caroline Medina, Thee Santos, Lindsay Mahowald, and Sharita Gruberg, "Protecting and Advancing Health Care for Transgender Adult Communities" (Washington: Center for American Progress, 2021), available at <https://www.americanprogress.org/article/protecting-advancing-health-care-transgender-adult-communities/>

<sup>12</sup> Lindsay Mahowald, "LGBTQ People of Color Encounter Heightened Discrimination" (Washington: Center for American Progress, 2021), available at <https://www.americanprogress.org/issues/lgbtq-rights/news/2021/06/24/500918/lgbtq-people-color-encounter-heightened-discrimination/>

<sup>13</sup> Caroline Medina, Lindsay Mahowald, Thee Santos, and Mia Ives-Ruble, "The United States Must Advance Economic Security for Disabled LGBTQI+ Workers" (Washington: Center for American Progress, 2021), available at <https://www.americanprogress.org/article/united-states-must-advance-economic-security-disabled-lgbtqi-workers/>

<sup>14</sup> National Academies of Sciences, Engineering, and Medicine, "Understanding the Wellbeing of LGBTQI+ Populations" (Washington: 2020), available at <https://www.nap.edu/read/25877/chapter/1>

<sup>15</sup> Federal Interagency Working Group on Improving Measurement of Sexual Orientation and Gender Identity in Federal Surveys, "Measurements of Sexual Orientation and Gender Identity in Federal Surveys," available at <https://nces.ed.gov/FCSM/pdf/buda5.pdf> (last accessed March 2021).

<sup>16</sup> Baker, Kellan E., Carl G. Streed Jr, and Laura E. Durso. "Ensuring That LGBTQI+ People Count—Collecting Data on Sexual Orientation, Gender Identity, and Intersex Status." *The New England Journal of Medicine* 384.13 (2021): 1184-1186.

providers offer person-centered care and services; and policymakers develop effective policy solutions to address disparities and assess progress on efforts to advance health equity and well-being at all ages.

## **II. The findings of the NASEM report**

The NASEM report represents the most comprehensive review to date of methodological evidence and measurement-related research for the constructs of sex, sexual orientation, gender identity, and variations in sex characteristics.<sup>17</sup> This consensus report, which was commissioned by 19 entities across the National Institutes of Health (NIH), was compiled by a committee of experts in data collection methodology and practice and comprehensively reviewed by 15 peer reviewers. It provides evidence to support adding measures of these constructs to surveys and research studies, administrative data systems, and clinical systems, accounting for differences related to the uses of data, identifiability of respondents, and the risk of data disclosure in each context. The report specifically recommends formats for a question about sexual orientation identity, a two-step measure of current gender and sex assigned at birth to identify transgender and cisgender respondents, and a standalone measure of intersex status. The report also issues important recommendations for areas of ongoing research, testing, and development to continue to improve these measures.

## **III. Recommended actions**

We respectfully urge HHS to seize the unique opportunity presented by this consensus report on evidence-based best practices by taking quick and decisive action to implement the recommendations issued by the NASEM panel. As the NASEM report makes clear, the recommended questions perform well in a variety of contexts, and there are substantial harms of continuing to exclude LGBTQI+ communities from agency efforts to enhance equitable data collection. Below we outline priority data collection mechanisms where we urge HHS to add these questions, as well as priority areas for future research.

### **Priority 1: Support the addition of recommended measures of sexual orientation, gender identity, and variations in sex characteristics to key HHS data collection mechanisms.**

Adding measures of sexual orientation, gender identity, and variations in sex characteristics to the following HHS-supported data collection mechanisms is a top priority for our organizations. These data collection instruments can collect valuable information on LGBTQI+ communities to shape policy interventions and inform the provision of services that promote more equitable outcomes. Their size will also allow for data disaggregation, which will facilitate analysis on populations that are living at the intersection of multiple marginalized identities, such as LGBTQI+ people with disabilities and LGBTQI+ Black, Indigenous, and other communities of color. Importantly, we also support

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<sup>17</sup> National Academies of Sciences, Engineering, and Medicine, “Measuring Sex, Gender Identity, and Sexual Orientation” (Washington: The National Academies Press, 2022), available at <https://www.nap.edu/catalog/26424/measuring-sex-gender-identity-and-sexual-orientation>

broad data collection on race, ethnicity, primary language, and disabilities in order to identify and address disparities that we know exist across our intersectional communities. We respectfully urge HHS to:

- Add sexual orientation, gender identity, and sex characteristics questions to the standardized demographic core questionnaire of the **Behavioral Risk Factor Surveillance System (BRFSS)**. In 2020, 32 states and Guam used the sexual orientation and gender identity optional question modules.<sup>18</sup> Including questions on sexual orientation, gender identity, and sex characteristics in the BRFSS core is crucial to collecting valuable population-based data on the health of LGBTQI+ adults across all 50 states and the U.S. territories.
- Add gender identity and variations in sex characteristics questions to the core measures of the **Youth Risk Behavior Surveillance System (YRBSS)**, which monitors health-related behaviors among youth and young adults. Including questions on gender identity and sex characteristics is especially critical to measuring the health and wellbeing of LGBTQI+ youth given the recent wave of legislative attacks on LGBTQI+ youth, especially transgender and nonbinary youth.
- Make permanent gender identity measures and add a measure of variations in sex characteristics to the **National Health Interview Survey**, which collects valuable information to monitor trends in health status, determine barriers to accessing care, and evaluate progress toward achieving national health objectives.
- Ensure the finalized **United States Core Data for Interoperability (USCDI) version 3** includes improved sex, sexual orientation, and gender identity data elements and adds a standalone intersex status data element. Specifically, we strongly support the Office of the National Coordinator adopting data elements designed in alignment with recommendations submitted by the Health Level Seven International (HL7) Gender Harmony Project.<sup>19</sup> Doing so is critical to better standardize the sharing of electronic health data classes and constituent data elements to foster interoperability in health information exchange, support care for LGBTQI+ patients in clinical contexts, and facilitate monitoring of LGBTQI+ population disparities in public health surveillance.
- Implement collection of information on sexual orientation, gender identity, and variations in sex characteristics in **every HHS program where demographic information of participants is collected**. These programs include CMS programs such as Medicare, Medicaid, and the Health Insurance Marketplace, as well as programs overseen by HHS operating divisions such as the Administration for Community Living, the Administration for Children and Families, the Health Resources and Services Administration, and others that

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<sup>18</sup> 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 March 2022).

<sup>19</sup> See 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](https://www.healthit.gov/isa/sites/isa/files/2022-04/HL7_GH_uscdi_response_03142022.pdf) (last accessed May 2022).

directly serve the public. While the existence of health disparities for LGBTQI+ people has been well-documented, their origins are not well understood. This is due in part to the fact that few high-quality, large-scale data sets exist in the very systems where those disparities occur. For example, CMS recently proposed a new information collection on the Model Medicare Advantage and Prescription Drug Plan application that did not include sexual orientation, gender identity, and variations in sex characteristics.<sup>20</sup> CMS did propose to add race and ethnicity questions to the Application and conduct cognitive testing of nonresponses to improve data collection. This information collection demonstrates that HHS can simultaneously require collection of demographic information and continue to test methods to improve data quality.<sup>21</sup> We encourage HHS to adopt the same approach with respect to data collection on sexual orientation, gender identity, and variations in sex characteristics in all of its programs. These data are essential for understanding whether and how LGBTQI+ people are equally served by HHS programs, projects, and activities and for ensuring that HHS upholds the civil rights of LGBTQI+ people.

- Ensure that **quality reporting** in all HHS-administered and -monitored programs includes information about and, where possible, stratification on participants' sexual orientation, gender identity, and variations in sex characteristics.

## **Priority 2: Invest in ongoing research to continue to develop, test, and improve measures of sexual orientation, gender identity, and sex characteristics.**

- Engage in testing to continue to **improve measurement of gender**. We specifically encourage HHS to fast-track research to increase the face validity of the second component of the recommended two-step gender identity question to ensure it optimally reflects the identities of transgender people. Potential enhancements include the opportunity for participants to select all responses that apply (e.g., “male” and “transgender”) and/or the addition of “nonbinary” as a response option. We note that the current evidence base finds a two-step format is critical to fully capture the complexity of gender, which incorporates both gender identity (i.e., identity as a man, a woman, or another gender) and gender modality (i.e., whether a person is transgender or cisgender).<sup>22</sup>
- Continue to invest in improving **administrative data collection** on gender identity, sex characteristics, and sexual orientation. For example, the Administration for Children and Families should rescind the 2019 policy that reversed the decision to collect information on

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<sup>20</sup> Model Medicare Advantage and Prescription Drug Plan Individual Enrollment Request (CMS-10718), Regulations.gov (May 5, 2022), <https://www.regulations.gov/document/CMS-2022-0013-0011>.

<sup>21</sup> As another example, see the recommendations made by the State Health Access Data Assistance Center (SHADAC) in response to the recent RFI on Medicaid and CHIP Access: State Health Access Data Assistance Center (SHADAC), “SHADAC Advocates a Data-based Approach to Advancing Medicaid and CHIP Access Monitoring Plan (Response to CMS Request for Information)” (April 29, 2022), <https://www.shadac.org/news/shadac-response-CMS-RFI-advancing-access>.

<sup>22</sup> Florence Ashley, “‘Trans’ is My Gender Modality,” in *Trans Bodies, Trans Selves*, 2nd edition (Oxford University Press, 2022): 22.

the sexual orientation, gender identity, and gender expression of children both in out-of-home care and of foster parents, adoptive parents, and legal guardians on the Adoption and Foster Care Analysis and Reporting System (AFCARS). Without transparent data, collected in a culturally competent manner, it is impossible to know whether we are meeting our responsibility to LGBTQI+ youth in state care, and we leave those youth at substantially greater risk for negative outcomes. A top priority in administrative data collection is the testing of alternative two-step gender measures that can identify transgender people in administrative data settings for aggregate statistical purposes without relying on sex assigned at birth, as collecting this information may be considered intrusive in situations where personally identifiable data are being maintained in employee or beneficiary files.<sup>23</sup>

- Test standalone measures that allow for **data collection on people with intersex traits**. This includes research to evaluate the comparative performance of the three measures identified in the NASEM report; the impacts of including definitions and examples in these questions; and the performance of proxy reporting, particularly among parents who report about their children.

**Priority 3: Provide guidance and support to facilitate an effective cross-agency approach to advancing data collection on sexual orientation, gender identity, and variations in sex characteristics.**

In order to advance this critical work in a consistent and coordinated manner across HHS, we request that HHS provide key guidance, personnel, and organizational resources required to successfully advance and organize these priorities across different departments. Specifically, we urge the following:

- HHS and individual departments must ensure these priorities are supported by **adequate staffing and requisite coordination** and ensure that departments regularly report back on progress. The Sexual and Gender Minority Research Office (SGMRO) has been an exemplary leader on LGBTQI+ equity efforts, but this has only been possible by having multiple, dedicated, permanent staff over a period of years. As such, we strongly support the recommendation in the President’s budget to dedicate more resources to this important work at NIH to continue the growth of the SGMRO and for the creation of a Center for Sexual Orientation and Gender Identity Research to be led by the SGMRO. HHS has been most effective on data and other equity initiatives in the past when they have been driven by both senior political and career staff who are knowledgeable and committed to action; have dedicated portfolios that include LGBTQI+ health and data collection issues; and who coordinate closely, with political leadership regularly bringing priorities to the Secretary for decisions and working hand-in-hand with career staff to ensure effective execution.

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<sup>23</sup> In addition to this research, agencies should consider issuing additional guidance on protecting the privacy of gender-related, medical, or other personal information for LGBTQI+ people, including under laws such as the Family Educational Rights and Privacy Act.

- HHS should revive the practice of releasing **annual LGBTQI+ reports**. When supported by adequate staffing, planning, and coordination, these reports have served as useful organizing mechanisms for making and tracking public commitments and driving implementation.

## Conclusion

Our organizations are united in voicing our strong support for HHS to add measures of sexual orientation, gender identity, and sex characteristics to HHS-supported data collection instruments, while simultaneously investing in and advancing research to continue to improve these measures. We will also be requesting a meeting to learn more about how our organizations can best support HHS' efforts to standardize and advance data collection on sexual orientation, gender identity, and variations in sex characteristics.

Thank you for your time and consideration, and for your efforts to advance equity and serve LGBTQI+ people and communities. Please do not hesitate to contact Kellan Baker at [KBaker@whitman-walker.org](mailto:KBaker@whitman-walker.org) or (202) 797-4417 if you need any additional information.

In partnership,

1. Advocates for Youth
2. American Psychological Association
3. APLA Health
4. Athlete Ally
5. Callen-Lorde Community Health Center
6. Campus Pride
7. CenterLink: The Community of LGBT Centers
8. Center for American Progress
9. CrescentCare
10. Evaluation, Technical Assistance, and Data Integration Program, Northwestern University  
Institute for Sexual and Gender Minority Health and Wellbeing
11. Fenway Health
12. FORGE, Inc.
13. GLMA: Health Professionals Advancing LGBTQ Equality
14. GLSEN
15. Howard Brown Health
16. Human Rights Campaign
17. interACT: Advocates for Intersex Youth
18. Jacobs Institute of Women's Health
19. Lambda Legal
20. Legacy Community Health
21. LGBTQ Victory Institute
22. Los Angeles LGBT Center
23. Mazzoni Center
24. Modern Military Association of America
25. Movement Advancement Project
26. NASTAD



27. National Black Justice Coalition
28. National Center for Lesbian Rights
29. National Center for Transgender Equality
30. National Coalition for LGBTQ Health
31. National Health Law Program
32. National LGBT Cancer Network
33. NorthLakes Community Clinic
34. PFLAG National
35. Positive Women's Network-USA
36. SAGE
37. The Center for LGBTQ Health Equity – Chase Brexton Health Care
38. The Trevor Project
39. Transhealth Northampton
40. Trillium Health
41. True Colors United
42. Whitman-Walker Institute