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October 3, 2022

Submitted via E-Mail to equitabledata@ostp.eop.gov

Dr. Arati Prabhakar
Director
White House Office of Science and Technology Policy
Executive Office of the President
Eisenhower Executive Office Building
1650 Pennsylvania Avenue
Washington, DC 20504

**RE: Request for Information; Federal Evidence
Agenda on LGBTQI+ Equity**

The National Health Law Program (NHeLP), founded in 1969, protects and advances the health rights of low-income and underserved individuals and families by advocating, educating, and litigating at the federal and state levels. NHeLP works to advance health equity and quality health care for all without bias or barriers. As such, we have long advocated for improved collection of demographic data in federal health programs to improve civil rights enforcement and the provision of culturally, linguistically appropriate, accessible care.

We thank you for the opportunity to provide input to the White House Office of Science and Technology Policy as you develop the Federal Evidence Agenda on LGBTQI+ Equity. NHeLP endorses the comments submitted by the Center for American Progress in response to this RFI. NHeLP comments separately to address the ways that data on sexual orientation, variations in sex characteristics, and gender identity (SOGISC) can be collected in health programs. Our comments will focus on three main areas of the RFI: 1) the value of collecting information

about LGBTQI+ populations in federal health programs; 2) the types of administrative data collections where such information would be valuable; and 3) recommended practices for collecting such information.

I. Federal Agencies Must Collect SOGISC Data to Understand LGBTQI+ Experiences

Existing evidence – mainly from community and nonprofit research – reveals that LGBTQI+ individuals face worse health outcomes and access to health care than non-LGBTQI+ individuals.¹ Yet these disparities are not well understood at a program level (as opposed to through research and surveys) because of lack of comprehensive data about LGBTQI+ experiences.

Collecting data helps federal agencies better understand LGBTQI+ experiences and address disparities in real time. For example, a recent survey found that one in four Transgender or Non-Binary individuals experienced a denial of health care in the past year.² Without comprehensive data about Transgender and Non-Binary individuals accessing a particular program, the program cannot understand where barriers happen and how to prevent them. Further, the program cannot determine how many Transgender people are able to access the program and what kind of specialty care Transgender people might need. This lack of understanding has civil rights implications as well; current evidence on disparities suggests that discrimination could potentially be a barrier to access, care, and overall health, and thus a cause of inequity.³ Without actual information about LGBTQI+ individuals who access or attempt to access the program, neither civil rights nor culturally appropriate care can be guaranteed.

¹ Caroline Medina & Lindsay Mahowald, *Advancing Health Care Nondiscrimination Protections for LGBTQI+ Communities*, CTR. FOR AM. PROGRESS (2022), <https://www.americanprogress.org/article/advancing-health-care-nondiscrimination-protections-for-lgbtqi-communities/>.

² *Id.*

³ *Id.*



II. HHS Should Set Standards for SOGISC Data Collection in Medicare, Medicaid, CHIP, and the Health Care Marketplace

We urge the Administration to prioritize demographic data collection in all federal programs that serve the public. In particular, we believe collecting this data in health programs, including Medicare, Medicaid, CHIP, and the Health Care Marketplace, will provide the most impactful and actionable information on LGBTQI+ inequity because it allows providers, plans, and programs to pinpoint where disparities occur. Collecting data at a population level enables effective study of smaller subpopulations, and particularly underserved populations at the intersections of multiple demographic characteristics, in a way that survey data cannot illuminate.

Collecting administrative data on LGBTQI+ populations also allows federal, state, and local governments to monitor and enforce access to entitlement programs in a way that meaningfully protects the civil rights of individuals and populations alike. Without real time information on the demographic makeup of populations served by each program, the Administration can only reactively respond to complaints of harm and discrimination, as opposed to proactively addressing inequities as they become apparent. In conjunction with the new Proposed Rule implementing § 1557 of the Affordable Care Act⁴ and the Executive Order on Advancing Equality for Lesbian, Gay, Bisexual, Transgender, Queer, and Intersex Individuals,⁵ the federal government must collect data to ensure that nondiscrimination is a reality for LGBTQI+ individuals in all aspects of health care.

Recent research advances, and commitments by the federal government, demonstrate the urgency and necessity of collecting SOGISC information in administrative data. HHS has already named demographic data collection of LGBTQI+ populations as a priority in the

⁴ Nondiscrimination in Health Programs and Activities, 87 Fed. Reg. 47824 (proposed Aug. 4, 2022), *available at* <https://www.federalregister.gov/documents/2022/08/04/2022-16217/nondiscrimination-in-health-programs-and-activities>.

⁵ Exec. Order No. 14075, 87 Fed. Reg. 37189 (Jun. 21, 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/>.



Strategic Plan⁶, Equity Action Plan,⁷ and the CMS Framework for Health Equity.⁸ Each of these documents names the need to collect data from program participants to “leverage quality improvement and other tools to ensure all individuals have access to equitable care and coverage,”⁹ track progress on core clinical measures that target high priority health conditions,¹⁰ and understand population health trends over time.¹¹ Further, HHS proposes to use administrative data to indicate whether its programs meet their equity goals.¹² Without gathering that administrative data, there can be no progress toward that goal.

III. Recommendations for Data Collection in Health Programs

We recommend that the Administration adopt the recommendations found in the recently released report *Measuring Sex, Gender Identity, and Sexual Orientation*.¹³ This consensus study provides expert recommendations on the best methods and scripts to use when collecting SOGISC demographic information on program applications and in the administrative setting.¹⁴ The research reviewed by the report demonstrates an incredibly high willingness to respond to questions about sexual orientation and gender identity in health care settings.¹⁵ The report also outlines additional research questions to improve future data collection on LGBTQI+ populations. We strongly encourage the Administration

⁶ U.S. DEP’T OF HEALTH & HUM. SERVS., STRATEGIC PLAN FY 2022-2026 (last visited Oct. 3, 2022), <https://www.hhs.gov/about/strategic-plan/2022-2026/index.html>.

⁷ U.S. DEP’T OF HEALTH & HUM. SERVS., EQUITY ACTION PLAN (Apr. 2022), <https://www.hhs.gov/sites/default/files/hhs-equity-action-plan.pdf>.

⁸ CTRS. FOR MEDICARE & MEDICAID SERVS., CMS FRAMEWORK FOR HEALTH EQUITY 2022-2032 (last visited Oct. 3, 2022), <https://www.cms.gov/files/document/cms-framework-health-equity.pdf>.

⁹ *Id.* at 10.

¹⁰ U.S. DEP’T OF HEALTH & HUM. SERVS., STRATEGIC PLAN FY 2022-2026, Objective 1.2 (accessed Oct. 3, 2022), <https://www.hhs.gov/about/strategic-plan/2022-2026/goal-1/objective-1-2/index.html>.

¹¹ CTRS. FOR MEDICARE & MEDICAID SERVS., CMS FRAMEWORK FOR HEALTH EQUITY 2022-2032 12 (accessed Oct. 3, 2022), <https://www.cms.gov/files/document/cms-framework-health-equity.pdf>.

¹² U.S. DEP’T OF HEALTH & HUM. SERVS., EQUITY ACTION PLAN 12-13 (Apr. 2022), <https://www.hhs.gov/sites/default/files/hhs-equity-action-plan.pdf>.

¹³ MEASURING SEX, GENDER IDENTITY, AND SEXUAL ORIENTATION (Nancy Bates et al. eds., 2022), available at <https://nap.nationalacademies.org/catalog/26424/measuring-sex-gender-identity-and-sexual-orientation>.

¹⁴ *Id.*

¹⁵ *Id.* at 55, 80. A study of Midwestern health clinics found that 82% of adults surveyed “endorsed the importance of collecting gender identity data, and just 3 percent expressed discomfort with the sexual orientation and gender identity questions they were asked.” *Id.* at 80.



to adopt the recommended data collection practices while continuing to test improvements to these practices.

Research and experience from community-based efforts can also inform practices adopted at the federal level. Studies show that educating both those collecting demographic data and those from whom demographic data is collected on the purpose of the data collection results in a higher response rate.¹⁶ Respondents should be informed of relevant privacy protections, including with whom the demographic information will be shared and where additional consent for disclosure must be given.¹⁷ We strongly recommend that the Administration adopt clear guidance on sharing SOGISC data in the health program context, with examples that illustrate how and where SOGISC information may be exchanged. The Administration should involve members of the LGBTQI+ community at every step of demographic data collection, from creating standards and language to collect such data, to analyzing the resulting data, to sharing the data with programs, researchers, and the broader population. Finally, we encourage the Administration to provide technical assistance and support to agencies as they develop practices to improve response rates at the point of collection. For example, the Fenway Institute developed a SOGI Data Toolkit¹⁸ and additional materials to support data collection implementation.¹⁹ The Administration should review available research and materials and provide support to agencies as they institute SOGISC data collection in their programs and activities.

¹⁶ See Chris Grasso et al., Planning and implementing sexual orientation and gender identity data collection in electronic health records, 26 J. AM. MED. INFORM. ASSOC. 66-70 (2019), available at <https://pubmed.ncbi.nlm.nih.gov/30445621/>; Sean Cahill et al., *Do Ask Do Tell: High Levels of Acceptability by Patients of Routine Collection of Sexual Orientation and Gender Identity Data in Four Diverse American Community Health Centers*, PLOS ONE (2014), available at <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0107104>.

¹⁷ See Caroline Medina & Lindsay Mahowald, *Collecting Data About LGBTQI+ and Other Sexual and Gender-Diverse Communities*, CTR. FOR AM. PROGRESS (May 24, 2022), <https://www.americanprogress.org/article/collecting-data-about-lgbtqi-and-other-sexual-and-gender-diverse-communities/>.

¹⁸ THE FENWAY INST., THE NUTS AND BOLTS OF SOGI DATA IMPLEMENTATION: A TROUBLESHOOTING TOOLKIT (2019), https://fenwayhealth.org/wp-content/uploads/TFI-54_SOGI-Data-Collection-Series-of-3-Tip-Sheets-for-pride-month_NutsAndBolts.pdf.

¹⁹ See, e.g., THE FENWAY INST., HELPING YOUR ORGANIZATION COLLECT SEXUAL ORIENTATION AND GENDER IDENTITY DATA (2019), https://fenwayhealth.org/wp-content/uploads/TFI-54_SOGI-Data-Collection-Series-of-3-Tip-Sheets-for-pride-month_HelpingYourOrganization.pdf; DO ASK DO TELL (last visited Oct. 3, 2022), <https://doaskdotell.org/>; NAT'L LGBTQIA+ HEALTH ED. CTR., SO/GI DATA COLLECTION DEMONSTRATION VIDEOS (last visited Oct. 3, 2022), <https://www.lgbtqiahealtheducation.org/courses/so-gi-data-collection-training/>.



IV. Conclusion

Thank you for considering our recommendations on how the Administration can use demographic data collection to further LGBTQI+ health equity. For more information on our comments, please contact Staff Attorney Charly Gilfoil at gilfoil@healthlaw.org.

Sincerely,



Charly Gilfoil
Staff Attorney

