

National HIV Surveillance System (NHSS)

Attachment 2(b)

Comment 1

June 6, 2022

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Submitted via *regulations.gov*

**RE: Proposed Data Collection Submitted for Public Comment and
Recommendations (RIN 2022-06917)**

To Whom It May Concern,

We are grateful for the opportunity to provide comments to the Centers for Disease Control and Prevention (“CDC”) on its above-captioned notice, which announces its intent to obtain approval of revised data collection instruments to be utilized as part of the National HIV Surveillance System (“NHSS”). *See* 87 Fed. Reg. 19,097 (April 01, 2022).

The undersigned are scholars affiliated with the Williams Institute at the UCLA School of Law. The Williams Institute is dedicated to conducting rigorous and independent research on sexual orientation and gender identity (“SOGI”), including on the health and wellbeing of lesbian, gay, bisexual, and transgender (“LGBT”) people. The Williams Institute collects and analyzes original data, as well as analyzes governmental and private data, and has long worked with federal agencies to improve data collection on the U.S. population. These efforts include producing widely-cited best practices for the collection of SOGI information on population-based surveys.¹

We write in response to the request by the CDC for comments on “whether the proposed collection of information is necessary for the proper performance of the functions of the agency, including whether the information will have practical utility” and on “the accuracy of the agency's estimate of the burden of the proposed collection of information, including the validity of the methodology and assumptions used[.]”² More specifically, we write in support of the CDC’s proposed addition of a measure asking for self-identified sexual orientation, and its maintaining of existing measures on gender identity. In Part I, we review provisions of law in support of this proposal, specifically those highlighting the proposal’s consistency with the mission and purposes of the NHSS and CDC. In Part II, we provide a brief review of research on LGBT people living with HIV—suggesting that patient-reported information on SOGI would assist the CDC in its goal of obtaining “quality, timely, and complete surveillance, and program data to guide HIV prevention efforts toward reducing new HIV infections and ending the HIV

¹ *See, e.g.*, GENDER IDENTITY IN U.S. SURVEILLANCE (GENIUSS) GROUP, WILLIAMS INST., BEST PRACTICES FOR ASKING QUESTIONS TO IDENTIFY TRANSGENDER AND OTHER GENDER MINORITY RESPONDENTS ON POPULATION-BASED SURVEYS (2014), <https://williamsinstitute.law.ucla.edu/wp-content/uploads/Survey-Measures-Trans-GenIUSS-Sep-2014.pdf>; SEXUAL MINORITY ASSESSMENT RESEARCH TEAM (SMART), WILLIAMS INST., BEST PRACTICES FOR ASKING QUESTIONS ABOUT SEXUAL ORIENTATION ON SURVEYS (2009), <https://williamsinstitute.law.ucla.edu/wp-content/uploads/Best-Practices-SO-Surveys-Nov-2009.pdf>.

² 87 Fed. Reg. at 19,098.

epidemic in the United States.”³ Finally, in Part III, we conclude by highlighting that the proposed items are consistent with existing research on best practices for the collection of SOGI information through surveys and other instruments, including measures recommended by an ad hoc panel formed by the National Academies of Sciences, Engineering, and Medicine, and with the existing practices of other federal agencies already collecting SOGI information.

I. The Proposal is Consistent with the Mission and Purposes of the NHSS and CDC

As noted by the CDC in its accompanying supporting materials, its proposal here is authorized by provisions of the Public Health Service Act allowing it to contract with states to engage in HIV surveillance.⁴ Those provisions do not preclude the CDC’s requiring the collection of SOGI or other information it sees fit to require, and indeed, call for it to prepare and distribute forms to allow for the uniformity of health data across contracting entities.⁵ Below, we highlight additional sources of law which support the CDC’s proposal, specifically those indicating that the required collection and evaluation of data specified by the CDC is consistent with Congress’s intended vision for the NHSS and the CDC’s administration of same.

First, we note that the CDC, through the Secretary of Health and Human Services (“the Secretary”), maintains a broad grant of authority from Congress through which it can require the collection of SOGI information as part of data collections it administers. As amended by the Patient Protection and Affordable Care Act, the Public Health Service Act mandates that the Secretary ensure that “any federally conducted or supported health care or public health program, activity or survey” collect and report information on individuals’ demographics, specifically their race, ethnicity, sex, primary language, and disability status.⁶ Notably, this provision also empowers the Secretary to call for the mandatory collection of “any other demographic data as deemed appropriate by the Secretary regarding health disparities.”⁷

Second, in addition to providing the CDC with broad latitude for determining which demographic information should be collected as part of federally conducted or supported data collection activities, other provisions in the Public Health Service Act highlight the role that Congress intended the CDC to play with respect to coordinating the data collected by and activities of state and local agencies involved with HIV surveillance and health care. For example, in providing funding for states to engage in reporting of cases of perinatal transmission of HIV, Congress left some determinations—such as determining the full scope of factors which may lead to such transmission—to the states, but ultimately calls for the Director of the CDC to be the one to “issue guidelines to ensure that the data collected is statistically valid.”⁸ The Secretary is charged under the Public Health Service Act with coordinating the “planning, funding, and implementation of Federal HIV programs”—with states and other entities in receipt of applicable funding being required to provide the Secretary with assurances that their programs will be coordinated with other available programs across the country.⁹ Similarly, states in receipt

³ 87 Fed. Reg. at 19,098.

⁴ 42 U.S.C. §§ 242b, 242k.

⁵ 42 U.S.C. § 242k(g).

⁶ 42 U.S.C. § 300kk(a)(1)(A).

⁷ 42 U.S.C. § 300kk(a)(1)(D).

⁸ 42 U.S.C. § 300ff(c).

⁹ 42 U.S.C. § 300ff-81.

of funding for early HIV intervention services are precluded from receiving grant funds unless their applications “provide[] assurances of compliance satisfactory to the Secretary” including “such agreements, assurances, and information as the Secretary determines to be necessary[.]”¹⁰

Finally, we note that this proposal is consistent with various recent policy directives related to health and equity. For example, the *National HIV/AIDS Strategy for the United States 2022–2025* provides several strategies through which agencies can “[e]nhance the quality, accessibility, sharing, and uses of data, including HIV prevention and care continua data and social determinants of health data[,]” such as by promoting the use of interoperable data standards developed by the Office of the National Coordinator for Health Information Technology.¹¹ Notably, said office has promulgated standards that call for the measurement of patient-identified sexual orientation, as well as patients’ gender identity.¹² Likewise, a recent executive order highlights the need for federal datasets to be disaggregated by “key demographic variables”—as the current lack of same “has cascading effects and impedes efforts to measure and advance equity.”¹³

II. Research Documents High Prevalence of HIV Diagnoses Among LGBT Populations

LGBT-identified people comprise approximately 4.5% of the U.S. adult population.¹⁴ We estimate that approximately 11 million adults in the U.S. identify as LGBT.¹⁵ This includes approximately 1.4 million adults who are transgender, comprising approximately 0.6% of the U.S. adult population.¹⁶ Similar to the country as a whole, the population of LGBT adults in the U.S. is demographically diverse. For example, drawing from Gallup Daily Tracking data collected between 2015 and 2017, we’ve previously estimated that 21% of LGBT adults identify as Latino/a or Hispanic, 12% as Black, and 5% as more than one race.¹⁷

Data previously collected by the CDC indicate that the HIV epidemic has had a disproportionate impact on LGBT people. For example, the CDC has estimated that among the 34,800 new HIV diagnoses in the U.S. in 2019, 70% (24,500) were attributed to individuals reporting male-to-male sexual contact.¹⁸ Among those reporting such contact—or in other

¹⁰ 42 U.S.C. § 300ff-65(2)–(3).

¹¹ WHITE HOUSE, NATIONAL HIV/AIDS STRATEGY FOR THE UNITED STATES 2022–2025 at 9 (2021), <https://hivgov-prod-v3.s3.amazonaws.com/s3fs-public/NHAS-2022-2025.pdf>.

¹² OFFICE OF THE NATIONAL COORDINATOR FOR HEALTH INFORMATION TECHNOLOGY, 2021 INTEROPERABILITY STANDARDS ADVISORY, REFERENCE EDITION 43–45 (2021), <https://www.healthit.gov/isa/sites/isa/files/inline-files/2021-ISA-Reference-Edition.pdf>.

¹³ Exec. Order 13985, Advancing Racial Equity and Support for Underserved Communities Through the Federal Government, 86 Fed. Reg. 7009 (Jan. 20, 2021).

¹⁴ KERITH J. CONRON & SHOSHANA K. GOLDBERG, WILLIAMS INST., ADULT LGBT POPULATION IN THE UNITED STATES 1 (2020), <https://williamsinstitute.law.ucla.edu/wp-content/uploads/LGBT-Adult-US-Pop-Jul-2020.pdf>.

¹⁵ *Id.*

¹⁶ ANDREW R. FLORES, JODY L. HERMAN, GARY J. GATES & TAYLOR N. T. BROWN, WILLIAMS INST., HOW MANY ADULTS IDENTIFY AS TRANSGENDER IN THE UNITED STATES? 3 (2016), <https://williamsinstitute.law.ucla.edu/publications/trans-adults-united-states>.

¹⁷ *LGBT Demographic Data Interactive*, WILLIAMS INST. (January 2019), <https://williamsinstitute.law.ucla.edu/visualization/lgbt-stats/?topic=LGBT#demographic>.

¹⁸ *HIV and Gay and Bisexual Men: HIV Incidence*, CDC.GOV (Sept. 16, 2021), <https://www.cdc.gov/hiv/group/msm/msm-content/incidence.html>; CDC, HIV SURVEILLANCE REPORT, 2019 at 13

words, gay, bisexual, and other men who have sex with men (“MSM”)—CDC research indicates that race likely plays a role in HIV incidence, with Black MSM as the most likely to report being impacted by HIV among groups monitored through the NHSS and other CDC data sources.¹⁹ The CDC estimates that 2% of new HIV diagnoses in 2019 were among transgender people.²⁰

The *National HIV/AIDS Strategy for the United States 2022–2025* states that previously collected national-level HIV surveillance data have been used to determine that transgender women and “gay, bisexual, and other men who have sex with men, in particular Black, Latino, and American Indian/Alaska Native men” are disproportionately affected by HIV, and therefore should be prioritized in efforts seeking to reduce disparities and improve HIV outcomes.²¹ While existing estimates indeed indicate a high prevalence of HIV diagnoses among certain LGBT subpopulations, better quality data is needed to fully verify and understand the implications of these findings, as up until this point the NHSS has not directly asked patients to report their sexual orientation identity, instead surmising that information through proxy questions on their recent sexual partners and experiences.

Data from surveys allowing for the direct identification of LGBT people, in particular those allowing for the identification of subpopulations based on multiple shared dimensions of identity, signal that there would be value in improving the quality of data collected through the NHSS. For example, in a recent study on LBQ women, we found that less than 1% of LBQ women were living with HIV, compared to 8% of GBQ men.²² However, when separating the group of LBQ women out by gender identity, we found different patterns including that 7% of transgender LBQ women were living with HIV.²³ NHSS data allowing for the direct identification of GBQ men—and others—is likely to enable researchers to verify whether differences might exist across specific sexual orientation identities; study the impact of holding such identifies alongside other dimensions of identity and social determinants of health; and provide insight into effective strategies for HIV treatment and prevention among specific subpopulations consistent with the CDC’s focus on targeted, “locally tailored” plans for same through its Ending the HIV Epidemic in the U.S. initiative.²⁴

III. The Proposed Items Are Consistent with Existing Research on SOGI Measurement

In light of existing research on the disproportionate impact of HIV among LGBT people, we commend the CDC for including the collection of information on patients’ SOGI within its proposed NHSS instruments here. Questions directly measuring sexual orientation identity have

(2021), <https://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-report-2018-updated-vol-32.pdf>.

¹⁹ *HIV and African American Gay and Bisexual Men*, CDC.GOV (Jan. 11, 2022)

<https://www.cdc.gov/hiv/group/msm/bmsm.html>.

²⁰ *HIV and Transgender People: HIV Diagnoses*, CDC.GOV (Apr. 13, 2022),

<https://www.cdc.gov/hiv/group/gender/transgender/hiv-diagnoses.html>.

²¹ WHITE HOUSE, *supra* note 11, at 25–26.

²² BIANCA D.M. WILSON, ALLEGRA R. GORDON, CHRISTY MALLORY, SOON KYU CHOI & M.V. LEE BADGETT, WILLIAMS INST., HEALTH AND SOCIOECONOMIC WELL-BEING OF LBQ WOMEN IN THE US 51 (2021), <https://williamsinstitute.law.ucla.edu/wp-content/uploads/LBQ-Women-Mar-2021.pdf>.

²³ *Id.*

²⁴ See, e.g., *Local Ending the HIV Epidemic in the U.S. Plans*, CDC.GOV (July 27, 2021) <https://www.cdc.gov/endhiv/action/local-ehe-plans.html>.

been included on federal surveys for over two decades.²⁵ Questions used to identify transgender respondents have been included on state and investigator-led surveys for some time, with more common use of both sexual orientation and gender identity questions, including in federal surveys, over the last decade.²⁶ A number of health-related federal data collections gather data on SOGI, including the All of Us Research Project by the National Institutes of Health,²⁷ the Health Resource and Services Administration's Health Center Patient Survey,²⁸ the Substance Abuse and Mental Health Services Administration's Performance Accountability and Reporting System,²⁹ and various surveys administered by the CDC itself.³⁰ The federal government has long engaged in its own review of best practices for the measurement of SOGI.³¹ Research on federal implementations of SOGI measures suggests that respondents are unlikely to consider SOGI information to be particularly sensitive, and would therefore provide such information if asked.³² Similarly, studies suggest that sexual minority people are not a population that is difficult to survey.³³

The federal government has also supported others' research on this topic, including by funding the research of an ad hoc panel formed by the National Academies of Sciences, Engineering, and Medicine on SOGI-related methodological issues (the "NASEM Panel").³⁴ The NASEM Panel's recommended measures were outlined in a recently released consensus

²⁵ See FEDERAL INTERAGENCY WORKING GROUP ON IMPROVING MEASUREMENT OF SEXUAL ORIENTATION AND GENDER IDENTITY IN FEDERAL SURVEYS, CURRENT MEASURES OF SEXUAL ORIENTATION AND GENDER IDENTITY IN FEDERAL SURVEYS 3 (2016), https://cpb-us-e1.wpmucdn.com/sites.northwestern.edu/dist/3/817/files/2017/01/WorkingGroupPaper1_CurrentMeasures_08-16-1xnai8d.pdf.

²⁶ Williams Institute Scholars, Comment Letter on Proposed Basic Demographic Items for the Current Population Survey (March 22, 2021), <https://williamsinstitute.law.ucla.edu/wp-content/uploads/Comment-CPS-Mar-2021.pdf>.

²⁷ *All of Us*, NIH.gov, <https://allofus.nih.gov> (last visited Aug. 16, 2021).

²⁸ BUREAU OF PRIMARY HEALTH CARE, HEALTH RESOURCE AND SERVICES ADMINISTRATION, HEALTH CENTER PATIENT SURVEY (HCPS), <https://www.cms.gov/files/document/sgm-clearinghouse-hcps-updated.pdf> (last visited Aug. 16, 2021).

²⁹ SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION, GOVERNMENT PERFORMANCE AND RESULTS ACT (GPRA) CLIENT OUTCOME MEASURES FOR DISCRETIONARY PROGRAMS (2019), <https://spars.samhsa.gov/sites/default/files/CSATGPRATool1.pdf>.

³⁰ See, e.g., CDC, 2021 NATIONAL HEALTH INTERVIEW SURVEY (NHIS) Questionnaire, https://ftp.cdc.gov/pub/Health_Statistics/NCHS/Survey_Questionnaires/NHIS/2021/EnglishQuest.pdf (last visited Aug. 16, 2021); CDC, NATIONAL ADULT TOBACCO SURVEY QUESTIONNAIRE, 2012-2013, https://www.cdc.gov/tobacco/data_statistics/surveys/nats/pdfs/2012-2013-questionnaire.pdf (last visited Aug. 16, 2021); NHANES 2019-2020 Questionnaire Instruments, CDC.GOV, <https://wwwn.cdc.gov/nchs/nhanes/continuousnhanes/questionnaires.aspx?BeginYear=2019> (last visited Aug. 16, 2021); 2019 BRFSS Survey Data and Documentation, CDC.GOV (Aug. 31, 2020), https://www.cdc.gov/brfss/annual_data/annual_2019.html; Questionnaires | YBRS, CDC.GOV (Nov. 17, 2020), <https://www.cdc.gov/healthyouth/data/yrbs/questionnaires.htm>.

³¹ See generally *Measuring Sexual Orientation and Gender Identity Research Group*, FED. COMM. STAT. METHODOLOGY (2018), <https://nces.ed.gov/FCSM/SOGI.asp>.

³² See, e.g., 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*, 9 PLOS ONE 1 (2014), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4157837/pdf/pone.0107104.pdf>.

³³ See, e.g., Nancy Bates et al., *Are Sexual Minorities Hard-to-Survey? Insights from the 2020 Census Barriers, Attitudes, and Motivators Study (CBAMS) Survey*, 35 J. OFFICIAL STATS. 709 (2019), <https://sciendo.com/article/10.2478/jos-2019-0030>.

³⁴ *Measuring Sex, Gender Identity, and Sexual Orientation for the National Institutes of Health*, NAT'L ACADEMIES OF SCIENCES, ENGINEERING, & MED., <https://www.nationalacademies.org/our-work/measuring-sex-gender-identity-and-sexual-orientation-for-the-national-institutes-of-health> (last visited Apr. 6, 2022).

study report,³⁵ offering guidance and best practices for collecting data on SOGI, and on variations in sex characteristics, in population-based surveys, as well as clinical and administrative settings—like those where the instruments proposed here would be utilized. The NASEM Panel’s report also provides guiding principles informing its recommendations, specifically inclusiveness, precision, respecting autonomy, collecting only necessary data, and a dedication to confidentiality.³⁶ The NASEM Panel’s recommended measures are consistent with those currently utilized by a number of federal agencies, such as the U.S. Census Bureau through its Household Pulse Survey measuring the impact of the COVID-19 pandemic,³⁷ and with the measures proposed by the CDC here. Those recommended measures have undergone extensive testing and have been observed to improve the “overall measurement quality” of studies.³⁸ Therefore, as scholars with extensive experience studying LGBT people, it is our opinion that the demand of the CDC’s proposed NHSS data collection is reasonable, and that this burden is offset by the benefits of knowledge to be gained on this population, which has been previously identified by the federal government as being at particular risk for HIV infection.³⁹

Available materials advise that the CDC maintains a practice of issuing unpublished guidance to states and other entities involved in implementing the NHSS to “ensure uniform reporting practices and provide standardized guidelines for HIV surveillance.”⁴⁰ However, notes in states’ surveillance reports indicate that while they have indeed been collecting data on patients’ gender identity—and more specifically, on their transgender status—for quite some time, some states continue to designate individuals based on their sex assigned at birth and are failing to characterize the specifics of HIV infection among transgender populations within their individual surveillance.⁴¹ We therefore recommend that the CDC consider exercising its legal authority as described above to ensure that participating entities are both collecting and reporting required data consistent with its forms, guidance, and research on best practices for same.

As scholars with experience in measurement development and testing, we would recommend that the CDC assess the performance of any implemented SOGI measures, and all other items, and making revisions as needed. Likewise, we note our concern with potential harm to respondents due to breach of confidentiality, and request that the CDC ensure that the data

³⁵ NAT’L ACADEMIES OF SCIENCES, ENGINEERING, & MED., MEASURING SEX, GENDER IDENTITY, AND SEXUAL ORIENTATION (2022), <https://nap.nationalacademies.org/catalog/26424/measuring-sex-gender-identity-and-sexual-orientation>.

³⁶ *Id.* at S-4.

³⁷ Thom File & Jason-Harold Lee, *Phase 3.2 of Census Bureau Survey Questions Now Include SOGI, Child Tax Credit, COVID Vaccination of Children*, U.S. Census Bureau (Aug. 05, 2021), <https://www.census.gov/library/stories/2021/08/household-pulse-survey-updates-sex-question-now-asks-sexual-orientation-and-gender-identity.html>.

³⁸ NAT’L ACADEMIES OF SCIENCES, ENGINEERING, & MED., *supra* note 35, at S-6, 5-9.

³⁹ *See, e.g.*, WHITE HOUSE, *supra* note 11, at 7.

⁴⁰ Stacy M. Cohen et al., CDC, *The Status of the National HIV Surveillance System, United States, 2013*, 129 PUB. HEALTH REP. 335–341 (2014), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4037459>.

⁴¹ *See, e.g.*, KENTUCKY CABINET FOR HEALTH AND FAMILY SERVICES, DEPARTMENT FOR PUBLIC HEALTH, HIV/AIDS SECTION, HIV/AIDS SURVEILLANCE REPORT 2021 at 4 (2021) <https://chfs.ky.gov/agencies/dph/dehp/hab/Documents/AnnualReport2021.pdf> (noting that “[s]ex designations in this report are based on a person’s sex assignment at birth. In May 2012, CDC issued guidance to state and local programs on methods for collecting data on transgender persons and working with transgender-specific data. However, characterization of HIV infection among transgender persons in Kentucky would require supplemental data from special studies.”).

contemplated here are collected and reported using all appropriate privacy standards. All entities responsible for NHSS data collection ought to ensure confidentiality of respondents' medical and demographic information.

Thank you for your consideration. Please direct any correspondence, including questions, to vasquezl@law.ucla.edu.

Respectfully Submitted,

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