The Williams Institute
UCLA SCHOOL OF LAW

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National Committee for Vital and Health Statistics
3311 Toledo Road
Hyattsville, MD 20782-2002
Submitted via email to: ncvhsmail@cdc.gov

RE: Full Committee Meeting (September 13-14, 2018)
Exploring Access to Small-area Population Health Data and Data Resources

Dear Committee Members:

We are grateful for the opportunity to submit public comments in reference to the agenda item "Exploring Access to Small-area Population Health Data and Data Resources" of the full committee meeting on September 13-14, 2018. We write to urge the Committee to take appropriate steps to protect and advance data collection at the U.S. Department of Health and Human Services ("HHS") about the health of sexual and gender minorities, including lesbian, gay, bisexual, and transgender ("LGBT") people. Health People 2020, among other sources, recognizes these data are crucial to better understanding and addressing a range of issues impacting the sexual and gender minority ("SGM") population, such as persistent health disparities compared to the general or non-SGM population.[1]

We are scholars at the Williams Institute, an academic research center at UCLA School of Law dedicated to conducting rigorous and independent research on sexual orientation and gender identity, including on the health and well-being of LGBT people. Our scholars collect and analyze original data as well as analyze governmental and private data. Williams Institute scholars also have extensive experience in designing and evaluating measures of sexual orientation and gender identity within population-based surveys, and have produced widely-utilized best practices.[2] Our scholars have long worked with federal agencies—including the Centers for Disease Control and Prevention, the National Center for Health Statistics, the Administration for Community Living, and other components of HHS—to improve data collection on the U.S. population. And we share a commitment with you and HHS to the development of data-informed, evidence-based policies and programs that promote health and well-being for all Americans.

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[1] U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion, Health People 2020 Topics & Objectives, Lesbian, Gay, Bisexual, and Transgender Health, https://www.healthypeople.gov/2020/topics-objectives/topic/lesbian-gay-bisexual-and-transgender-health.

[2] *See* Sexual Minority Assessment Research Team, Williams Institute, *Best Practices for Asking Questions about Sexual Orientation on Surveys* (2009), https://williamsinstitute.law.ucla.edu/wp-content/uploads/SMART-FINAL-Nov-2009.pdf; Gender Identity in U.S. Surveillance Group, Williams Institute, *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/geniuss-report-sep-2014.pdf.

In this comment, *first*, we urge the Committee to advise and assist HHS in continuing to be a leader in advancing collection of data about SGM populations, as well as in analyzing, disseminating, and applying those data to inform HHS policies and programs. With respect to small-area estimation, in particular, we acknowledge there computational challenges with small-area estimation for LGBT people given the low base rate, and we urge the Committee to support research that would address any such challenges and make small-area estimation feasible. *Second*, to assist the Committee in implementing our recommendations, we briefly describe recent developments with respect to four surveys in health contexts where sexual orientation and gender identity data collection have been recently endangered or could be improved or secured. We welcome any opportunity to assist the Committee in these efforts.

I. HHS Must Remain a Leader In Data Collection Relevant to SGM Populations

As NCVHS members are undoubtedly aware, the U.S. public health surveillance system, including a wide range of surveys and administrative collections, has only recently begun to incorporate data items designed to identify SGM people, especially LGBT-identified people. As we recently explained in a letter to the CDC, "[o]nly a handful of more than 150 data sources and dozens of surveys that are used to monitor progress towards Healthy People 2020 objectives include direct sexual orientation and gender identity items."[3] As a result, legislators, policymakers, agencies at all levels of government, courts, public health departments, medical providers, academic researchers, social service providers, businesses, and others are deprived crucial knowledge about SGM populations (including subpopulations, such as people of color, bisexuals, intersex people, or people living in particular places). And without such information, these various actors are disadvantaged with regard to the design of evidence-based policies, programs, and services that meet the unique and common health needs of SGM people and their families.

Recognizing the importance of expanding and improving federal data collection on SGM populations, the Office of Management and Budget convened in 2015 the Federal Interagency Working Group on Improving Measurement of Sexual Orientation and Gender Identity in Federal Surveys ("Interagency Working Group"). In its first of three reports, the Interagency Working Group explained:

> At a time when sexual and gender minority (SGM) populations are becoming more visible in social and political life, there remains a lack of data on the characteristics and well-being of these groups. In order to understand the diverse needs of SGM populations, more representative and better quality data need to be collected.[4]

[3] Appendix C (citing https://www.healthypeople.gov/2020/data-search/Data-Sources). Among these, a few surveys, such as the American Community Survey and the Current Population Survey, allow for identification and analysis of cohabiting same-sex couples. But cohabiting same-sex couples is only one particular subgroup of the SGM population and same-sex couples' characteristics do not necessarily reflect the broader LGBT or SGM populations. Other federal data collections, including both surveys and administrative data, do not even allow for the identification of same-sex couples.

[4] 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* (2016),

Even before the Interagency Working Group was convened, HHS was a leader among the federal Executive departments in developing and implementing measures of sexual orientation and gender identity in population-based surveys and other data collections, analyzing and disseminating those data, and addressing methodological issues along the way. Indeed, in 2011, Secretary Sebelius "announced HHS' plans to greatly enhance the collection of health data on LGBT populations [because g]athering data on LGBT individuals will help researchers, policy makers, health care providers, and advocates identify and address health disparities affecting the LGBT population."[5] Likewise, in 2012, HHS made the following commitment:

> The Department will continue to work toward increasing the number of federally-funded health and demographic surveys that collect and report sexual orientation and gender identity data, consistent with the President's support for evidence-based policies. In collaboration with other agencies throughout HHS, the Centers for Disease Control and Prevention (CDC) is leading an effort to develop and test questions on sexual orientation and gender identity. The Office of the Assistant Secretary for Health is also reviewing existing LGBT data and will generate baselines and targets addressing LGBT health disparities through the Healthy People 2020 initiative. This process will include meetings with LGBT data experts and stakeholders to provide transparency and opportunities for input.[6]

As a result of these efforts, a variety of surveys within HHS added measures of sexual orientation and/or gender identity. For example, since 2013, the National Health Interview Survey ("NHIS") has included a sexual orientation question; since 2014, the Behavioral Risk Factor Surveillance System ("BRFSS") has included a CDC-sponsored optional module with sexual orientation and gender identity items; and since 2015, the National Youth Risk Behavior Survey has included a measure of sexual orientation.[7] Even before Secretary Sebelius's 2011 announcement, some HHS-sponsored or -funded surveys collected sexual orientation

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https://s3.amazonaws.com/sitesusa/wp-content/uploads/sites/242/2014/04/WorkingGroupPaper1_CurrentMeasures_08-16.pdf.

[5] U.S. Department of Health and Human Services, *Better Health and Well-Being: Making Improvements for Lesbian, Gay, Bisexual, and Transgender (LGBT) Americans* (2012), https://www.hhs.gov/sites/default/files/lgbt-health-update-2011.pdf

[6] U.S. Department of Health and Human Services, *Recommended Actions to Improve the Health and Well-Being of Lesbian, Gay, Bisexual, and Transgender Communities* (2012), https://www.hhs.gov/programs/topic-sites/lgbt/enhanced-resources/reports/health-objectives-2011/index.html.

[7] *See also* 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* (2016), https://s3.amazonaws.com/sitesusa/wp-content/uploads/sites/242/2014/04/WorkingGroupPaper1_CurrentMeasures_08-16.pdf.

information from respondents, such as the National Intimate Sexual Violence Survey ("NISVS")[8] and the National Survey of Family Growth (NSFG).[9]

And these data sources have yield valuable information. For example:

- NCHS analysis of NHIS data found that LGB people are more likely to be current cigarette smokers than their straight counterparts; bisexuals report a higher rate of serious psychological distress in the past 30 days than people who identify as straight; and lesbians aged 18 to 64 are more likely than their straight counterparts to report not obtaining needed medical care in the past year due to cost.[10] Williams Institute and other researchers have analyzed NHIS data stratified by sexual orientation to study, for example, food insecurity and SNAP participation;[11] insurance coverage and binge drinking;[12] and health indicators for older sexual minorities.[13] And a recent study using NHIS data finds that bisexuals are much more likely to be poor than heterosexuals, lesbians, and gay men.[14]
- With respect to the BFRSS, we recently detailed that "analyses of [these] data produced knowledge about the health of LGBT adults and specific LGBT subgroups (e.g., veterans, cancer survivors, rural residents) across a broad array of issues, including physical and mental health, violence victimization, disability, and health insurance coverage. The BRFSS has also provided a unique source of information about the prevalence of socioeconomic (e.g., education, employment, income) and behavioral determinants of health such as smoking, drinking, diet, activity, and screening (e.g., HIV, colorectal, and pap testing) which is necessary to ensure that LGBT people are included in

[8] M.L. Walters et al., National Center for Injury Prevention and Control, *Centers for Disease Control and Prevention, The National Intimate Partner and Sexual Violence Survey (NISVS): 2010 Findings on Victimization by Sexual Orientation* 5 (2013), https://www.cdc.gov/violenceprevention/pdf/nisvs_sofindings.pdf.

[9] *See* Anjani Chandra et al., Sexual Behavior, Sexual Attraction, and Sexual Identity in the United States: Data From the 2006–2008 National Survey of Family Growth, 36 *National Health Statistics Reports* 1 (Mar. 3, 2011), https://www.cdc.gov/nchs/data/nhsr/nhsr036.pdf.

[10] Brian W. Ward et al., Sexual Orientation and Health Among U.S. Adults: National Health Interview Survey, 2013 *National Health Statistics Reports* (2014), https://www.cdc.gov/nchs/data/nhsr/nhsr077.pdf.

[11] Taylor N.T. Brown et al., Williams Institute, *Food Insecurity and SNAP Participation in the LGBT Community* (2016), https://williamsinstitute.law.ucla.edu/wp-content/uploads/Food-Insecurity-and-SNAP-Participation-in-the-LGBT-Community.pdf.

[12] Mitchell R. Lunn et al., Sociodemographic Characteristics and Health Outcomes Among Lesbian, Gay, and Bisexual U.S. Adults Using Healthy People 2020 Leading Health Indicators, 4 *LGBT Health* 283 (2017).

[13] Christina N. Dragon et al., "Health indicators for older sexual minorities: National health interview survey, 2013-2014," 4 *LGBT Health* 1 (2017).

[14] M.V. Lee Badgett, Left Out? Lesbian, Gay, and Bisexual Poverty in the U.S., *Population Research Policy Review* (2018).

prevention and intervention efforts. Additionally, BRFSS data have been utilized to examine the relationship between public policies and health."[15]

- CDC analysis of the 2015 National Youth Risk Behavior Survey showed that, among other findings, 10% of LGB students, compared with 5% of heterosexual students, reported being threatened or injured with a weapon on school property, and 34% of LGB students, compared with 19% of heterosexual students, reported being bullied on school property.[16]
- CDC analysis of NISVS data shows that LGB people experience intimate partner violence at similar, if not higher, rates than their heterosexual counterparts, with especially high rates of intimate partner and sexual violence against bisexuals.[17] The NISVS data highlight not only "the broad range of violence experienced by LGB individuals in the United States" but also the need for "immediate, but thoughtful, actions to prevent and respond to the violence occurring within LGB populations. A more comprehensive plan for violence prevention that includes LGB individuals is needed to address issues that include effective prevention efforts . . . ."[18]

And other Executive departments have followed HHS's lead. For example, in 2016, the Bureau of Justice Statistics added measures of sexual orientation and gender identity to the National Crime Victimization Survey. The measure of sexual orientation used on the NCVS was adopted from the NHIS.

For all of these reasons, we urge the Committee to take appropriate steps to maintain HHS as a leader on SGM data collection, including by working to maintain and improve existing data collections inclusive of sexual orientation and gender identity items, and by working to expand the range and number of HHS data collections that include these measures. With respect to small-area estimation, in particular, we acknowledge there computational challenges with small-area estimation for LGBT people given the low base rate, and we urge the Committee to support research that would address any such challenges and make small-area estimation feasible. A better, fuller understanding of the health and well-being of SGM populations will help HHS get closer to achieving not only its Healthy People goals and initiatives, but also its very mission of enhancing the health and well-being of all Americans.

II. Recent Developments: Four Examples

To assist the Committee on our above recommendation, here we briefly describe recent developments with respect to four HHS data collections where sexual orientation and gender identity data collection could be advanced and/or are/were at risk: (A) the Adoption and Foster

[15] Appendix C at 1-2; *see also id.* at 25-57 (annotated bibliography).

[16] Laura Kann et al., Sexual Identity, Sex of Sexual Contacts, and Health-Related Behaviors Among Students in Grades 9-12—United States and Selected Sites, 2015, 65 *Morbidity & Mortality Weekly Report* 1, 11, 15 (Aug. 12, 2016), https://www.cdc.gov/mmwr/volumes/65/ss/pdfs/ss6509.pdf.

[17] *Id.* at 1.

[18] *Id.* at 38.

Care Analysis and Reporting System, (B) the National Survey of Older American Act Participants, (C) the Behavioral Risk Factor Surveillance System, and (D) National Health Interview Survey. Included as appendices to this letter are public comments we have recently filed on each of these data collections. These four surveys are meant to be examples and not an exhaustive accounting.

A. Adoption and Foster Care Analysis and Reporting System

In December 2016, the Administration on Children, Youth and Families ("ACYF") issued a Final Rule that updated and streamlined the Adoption and Foster Care Analysis and Reporting System, also known as AFCARS.[19] Among other changes, the Final Rule adopted data elements related to the sexual orientation of a child, the child's foster patent(s), and adoptive parent(s) or legal guardian(s), as well as data elements related to family conflict over a child's sexual orientation, gender identity, and gender expression.[20] The Final Rule explains why these data are important, including "to better support children and youth in foster care who identify as LGBTQ and ensure that foster care placement resources and services are designed appropriately to meet their needs."[21] As we recently explained in a public comment the ACYF, existing research finds that "LGBTQ youth are disproportionately overrepresented in foster care and suffer worse safety, permanency, and well-being outcomes than their non-LGBTQ peers."[22] Thus, with respect to children, these data elements are important "so that states and tribes can improve outcomes, identify and fund needed resources, and reduce disparities experienced by [LGBTQ] foster children."[23]

The 2016 Final Rule set an October 2019 deadline for states and tribes to implement the various changes directed by the Rule. However, in March 2018, ACYF issued an Advance Notice of Proposed Rulemaking that delayed the implementation of the Final Rule in order for ACYF revisit the data elements described above.[24] Please see **Appendix A** for more information.

B. National Survey of Older American Act Participants

In March 2017, the Administration for Community Living ("ACL") announced the Proposed 2017 National Survey of Older American Act Participants, stating incorrectly that no changes were made to the survey instrument.[25] In fact, the 2017 proposed survey had removed an item that asked respondents about their sexual orientation that had existed on prior iterations of the NSOAAP. The NSOAAP, as the Committee knows, is an important survey that provides

[19] 81 Fed. Reg. 90524 (Dec. 14, 2016).

[20] 81 Fed. Reg. 90526.

[21] 81 Fed. Reg. 90534.

[22] Appendix A at 2.

[23] *Id.*

[24] 83 Fed. Reg. 11449 (Mar. 15, 2018).

[25] Proposed Extension with No Changes of a Currently Approved Collection; National Survey of Older Americans Act Participants, 82 Fed. Reg. 13457 (March 13, 2017).

critical data to evaluate Area Agencies on Aging and the vital services they provide to older people.

ACL asserted that the removal was appropriate because—as we paraphrased in a public comment to ACL—"the relatively small sample sizes of the individual surveys that comprise the NSOAAP, combined with the low base rate of LGBT people in the general population, result in surveys yielding a relatively small number of NSOAAP respondents who identify as LGBT in any given year."[26] In response, we stated: "As scholars who analyze data and are committed to producing reliable estimates, we appreciate that there are methodological challenges related to the small size of the LGBT population. . . . Nonetheless, we urge ACL to investigate and attempt to address limitations related to the small population size by identifying alternative approaches to sampling."[27] And we provided some recommendations, such as pooling data over years and over-sampling.

Following the notice and comment period, ACL reversed its decision and reinstated an improved sexual orientation question on the NSOAAP. We commend ACL for this decision. We bring this example to the Committee's attention to highlight what will likely be a continuing methodological concern for inclusion of measures of sexual orientation and, especially, gender identity on surveys, as well as suggestions for addressing those issues. We also note that the NSOAAP does not contain a gender identity item that allows for identification of transgender individuals; therefore, these data provide no information about transgender older adults. Please see **Appendix B** for more information.

C. Behavioral Risk Factor Surveillance System

As stated above in Part I, the BRFSS includes a CDC-sponsored optional module with sexual orientation and gender identity items, meaning that states may but need not adopt the module. We understand that HHS funding for this module has been uncertain over the years, putting the module at risk. As we recently explained to the CDC, "we strongly recommend that SOGI questions be added to the core survey so that they are asked of residents across all 50 states, US territories, and the District of Columbia. Like other demographic items on the BRFSS, the SOGI items belong on the demographic section of the core survey where they will be utilized uniformly across the states. At the very least, we urge the CDC to continue to offer the SOGI optional module, to process and analyze these data, and to encourage states to adopt the module with incentives. In addition, we urge the CDC to identify a division at CDC or external source to commit to financially sponsor the SOGI module in 2019 and into the future."[28]

We commend the CDC for its continued commitment to collecting sexual orientation and gender identity information on the BRFSS, its efforts to expand the states that adopt the optional SOGI module, and its efforts to support moving the SOGI items on the core survey's demographic section. Please see **Appendix C** for more information.

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[26] Appendix B at 3.

[27] *Id.*

[28] Appendix C at 2.

D. The National Health Interview Survey

As stated above in Part I, the NHIS includes a measure of sexual orientation that yields valuable health information, and we commend NCHS for its development of and commitment to this item. As we recently explained in a public comment, "the continued collection of such data is crucial to the ability to measure and track a wide variety of health indicators and outcomes as they apply to sexual minority populations, and such research helps to inform policy making and resource allocation based on the specific needs of these communities."[29]

But the NHIS does not include questions designed to identify transgender respondents. As our comment further explained, "[w]e urge the CDC to revise the existing NHIS gender item by adding the two-step approach to measuring gender identity, which would allow researchers to analyze health disparities facing the transgender population. The CDC's HIV case report, the National Crime Victimization Survey, the California Health Interview Survey, and other population-based surveys have successfully added gender identity questions that measure transgender status, indicating that NHIS could do so as well. The documentation of pervasive discrimination against transgender people in the United States, including in healthcare contexts, makes the NHIS a critical survey for understanding healthcare access, utilization experiences, and the health profile of the transgender population."[30] Please see **Appendix D** for more information.

Conclusion

We thank the Committee for its invaluable service to improving and deepening our knowledge of health in the United States, including with respect to minority populations. We urge the Committee to advise and assist HHS in maintaining and improving existing data collection on SGM populations, and to identify new surveys and administrative collections where such data should be collected. The Williams Institute welcomes the opportunity to assist the NCVHS in these efforts. Thank you for your consideration.

Respectfully Submitted,

Adam P. Romero, J.D.
Director of Legal Scholarship and Federal Policy
and Arnold D. Kassoy Scholar of Law
The Williams Institute
Lecturer-in-Law
UCLA School of Law
romero@law.ucla.edu

(Signatures continued on next page)

[29] Appendix D at 2.

[30] *Id.* at 3.

M.V. Lee Badgett, Ph.D.
Professor of Economics
Faculty and former Director, School of Public Policy
University of Massachusetts Amherst
and
Williams Distinguished Scholar
The Williams Institute
UCLA School of Law

Kerith J. Conron, Sc.D., M.P.H.
Blachford-Cooper Distinguished Scholar and Research Director
The Williams Institute
UCLA School of Law

Andrew R. Flores, Ph.D.
Assistant Professor of Political Science
Quigley Fellow
Department of Public Policy & Political Science
Lorry I. Lokey School of Business & Public Policy
Mills College
and
Visiting Scholar
The Williams Institute
UCLA School of Law

Nanette Gartrell, M.D.
Visiting Distinguished Scholar
The Williams Institute
UCLA School of Law

Ilan H. Meyer, Ph.D.
Williams Distinguished Senior Scholar of Public Policy
The Williams Institute
UCLA School of Law
Adjunct Professor of Community Health Sciences
UCLA Fielding School of Public Health

Bianca D.M. Wilson, Ph.D.
Rabbi Barbara Zacky Senior Scholar of Public Policy
The Williams Institute
UCLA School of Law