

August 19, 2021

Jolie Matthews  
National Association of Insurance Commissioners  
*Via e-mail*

**RE: Draft Principles of Data Collection**

To Whom It May Concern,

We are grateful for the opportunity to provide comments to the National Association of Insurance Commissioners (“NAIC”) on the draft “Principles of Data Collection” document (the “Draft Principles”) prepared by its Special Committee on Race and Insurance.

The undersigned are scholars affiliated with the Williams Institute, a center at the UCLA School of Law dedicated to conducting rigorous and independent research on sexual orientation and gender identity (“SOGI”), including on health disparities faced by 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.<sup>1</sup>

We write to commend the NAIC for its inclusion of SOGI measures, and its recommendation that they be “systemically” utilized by health insurance companies, within the Draft Principles. Williams Institute research shows that LGBT people report various health disparities across the life course as compared to their non-LGBT peers, including evidence of worse mental and physical health outcomes as a result of experiencing stigma.<sup>2</sup> Additionally, our research has found that LGBT people can be particularly vulnerable to certain health risks. For example, in a study focused on California, we found that many LGBT adults reported underlying health conditions that put them at increased risk of serious illness related to COVID-

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<sup>1</sup> 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>.

<sup>2</sup> See generally ILAN H. MEYER, BIANCA D.M. WILSON, & KATHRYN O’NEILL, WILLIAMS INST., LGBTQ PEOPLE IN THE US: SELECT FINDINGS FROM THE GENERATIONS AND TRANSPop STUDIES (2021), <https://williamsinstitute.law.ucla.edu/wp-content/uploads/Generations-TransPop-Toplines-Jun-2021.pdf>; DAVID M. FROST, KEREN LEHAVOT, & ILAN H. MEYER, WILLIAMS INST., MINORITY STRESS AND PHYSICAL HEALTH AMONG SEXUAL MINORITY INDIVIDUALS (2015), <https://williamsinstitute.law.ucla.edu/publications/minority-stress-physical-health/>; ILAN H. MEYER & DAVID M. FROST, WILLIAMS INST., MINORITY STRESS AND THE HEALTH OF SEXUAL MINORITIES (2013), <https://williamsinstitute.law.ucla.edu/publications/minority-stress-health-sm/>.

19, such as asthma, diabetes, and heart disease.<sup>3</sup> Our research also shows that most LGBT people reporting facing challenges in accessing health care, though only about 10% of LGBT people are uninsured,<sup>4</sup> suggesting causes beyond affordability. In many cases, LGBT people report negative health outcomes at rates consistent with those reported by people of color<sup>5</sup>—with LGBT people of color then often reporting their own unique and significant experiences with marginalization.<sup>6</sup> For example, we recently found that LGBT people of color are more likely than non-LGBT White people to report experiencing the negative health and financial impacts of the COVID-19 pandemic.<sup>7</sup>

Without comprehensive data from private and public sources on the demographics and experiences of LGBT people, including on their specific needs and social determinants of health, medical providers may be limited in their ability to provide the highest quality care to LGBT patients.<sup>8</sup> Similarly, researchers and policymakers may be restricted in their ability to develop appropriate statutory, regulatory, and other interventions to the systemic issues faced by LGBT people in health care settings. Finally, efforts to address health disparities, in particular those which exist along multiple lines of marginalization (e.g., race *and* sexual orientation), will likely be limited if there is a lack of data through which to inform them and assess their success.

Research has shown that data on SOGI can be reliably collected, including that respondents are unlikely to consider SOGI information to be particularly sensitive and would therefore provide it if asked,<sup>9</sup> and that sexual minority people are not a population that is difficult to survey.<sup>10</sup> Additionally, the federal government has long engaged in its own research on best practices for measuring SOGI, including through a federal interagency working group organized

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<sup>3</sup> KATHRYN O'NEILL, WILLIAMS INST., HEALTH VULNERABILITIES TO COVID-19 AMONG LGBT ADULTS IN CALIFORNIA 1 (2020), <https://williamsinstitute.law.ucla.edu/wp-content/uploads/LGBT-COVID-CA-Health-May-2020.pdf>.

<sup>4</sup> MEYER, WILSON, & O'NEILL, *supra* note 2, at 27–28.

<sup>5</sup> *See, e.g.*, BRAD SEARS, KERITH J. CONRON, & ANDREW R. FLORES, WILLIAMS INST., THE IMPACT OF THE FALL 2020 COVID-19 SURGE ON LGBT PEOPLE IN THE US 8–9 (2021), <https://williamsinstitute.law.ucla.edu/wp-content/uploads/COVID-LGBT-Fall-Surge-Feb-2021.pdf> (finding that 10.3% of LGBT people, and 10.6% of non-LGBT people of color, reported testing positive for COVID-19).

<sup>6</sup> *See, e.g.*, SOON KYU CHOI, BIANCA D.M. WILSON, & CHRISTY MALLORY, WILLIAMS INST., BLACK LGBT ADULTS IN THE US 18 (2021), <https://williamsinstitute.law.ucla.edu/publications/black-lgbt-adults-in-the-us/> (finding that 26% of Black LGBT adults have been diagnosed with depression, compared to 15% of Black non-LGBT adults, with Black LGBT (29%) and non-LGBT (17%) women being more likely to be diagnosed with depression than Black LGBT (21%) and non-LGBT (12%) men).

<sup>7</sup> CHRISTY MALLORY, BRAD SEARS, & ANDREW R. FLORES, WILLIAMS INST., COVID-19 AND LGBT ADULTS AGES 45 AND OLDER IN THE US (2021), <https://williamsinstitute.law.ucla.edu/wp-content/uploads/COVID-LGBT-45-May-2021.pdf>; SEARS, CONRON, & FLORES, *supra* note 5.

<sup>8</sup> HHS Press Office, *HHS Updates Interoperability Standards to Support the Electronic Exchange of Sexual Orientation, Gender Identity and Social Determinants of Health*, HHS.GOV (July 9, 2021), <https://www.hhs.gov/about/news/2021/07/09/hhs-updates-interoperability-standards-to-support-electronic-exchange-of-sogi-sdoh.html>.

<sup>9</sup> *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>.

<sup>10</sup> *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>.

by the Federal Committee on Statistical Methodology,<sup>11</sup> and a committee formed by the National Academies of Sciences, Engineering, and Medicine (the “NASEM Committee”).<sup>12</sup>

In its recent consensus study, the NASEM Committee notes that “[e]ffectively addressing disparities related to sexual orientation, gender identity, and intersex status will require collaborative and coordinated efforts among federal, state, and private stakeholders.”<sup>13</sup> A number of health-related federal data collections already gather data on SOGI, including the All of Us Research Project of the National Institutes of Health,<sup>14</sup> the Health Center Patient Survey administered by Health Resource and Services Administration,<sup>15</sup> the Substance Abuse and Mental Health Services Administration’s Performance Accountability and Reporting System,<sup>16</sup> and various surveys by the Centers for Disease Control and Prevention.<sup>17</sup> Additionally, the U.S. Department of Health and Human Services recently updated its Interoperability Standards to call for the standardized collection of SOGI data in clinical settings.<sup>18</sup> The NASEM Committee’s study recommends collecting SOGI data through a variety of means, including “electronic health records . . . and administrative data systems, including intake forms.”<sup>19</sup> As a key stakeholder in the provision of health care to millions across the U.S., insurance companies should therefore join the federal government in these efforts and begin work to consistently collect, maintain, protect, and report data on SOGI alongside other demographic measures.

Thank you for your consideration. Please direct any correspondence to [vasquezl@law.ucla.edu](mailto:vasquezl@law.ucla.edu).

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<sup>11</sup> See generally *Measuring Sexual Orientation and Gender Identity Research Group*, FED. COMM. STAT. METHODOLOGY (2018), <https://nces.ed.gov/FCSM/SOGI.asp>.

<sup>12</sup> *Understanding the Status and Well-Being of Sexual and Gender Diverse Populations*, NAT’L ACADEMIES OF SCIENCES, ENGINEERING, & MED., <https://www.nationalacademies.org/our-work/understanding-the-status-and-well-being-of-sexual-and-gender-diverse-populations> (last visited Aug. 16, 2021).

<sup>13</sup> COMMITTEE ON UNDERSTANDING THE WELL-BEING OF SEXUAL AND GENDER DIVERSE POPULATIONS, NAT’L ACADEMIES OF SCIENCES, ENGINEERING, & MED., UNDERSTANDING THE WELL-BEING OF LGBTQI+ POPULATIONS 398 (2020), <https://www.nap.edu/read/25877/chapter/20#398>.

<sup>14</sup> *All of Us*, NIH.gov, <https://allofus.nih.gov> (last visited Aug. 16, 2021).

<sup>15</sup> 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).

<sup>16</sup> 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>.

<sup>17</sup> See, e.g., CDC, NATIONAL HIV BEHAVIORAL SURVEILLANCE (NHBS), <https://www.cms.gov/files/document/sgm-clearinghouse-nhbs.pdf> (last visited Aug. 16, 2021); CDC, 2021 NATIONAL HEALTH INTERVIEW SURVEY (NHIS) Questionnaire, [https://ftp.cdc.gov/pub/Health\\_Statistics/NCHS/Survey\\_Questionnaires/NHIS/2021/EnglishQuest.pdf](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](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://www.cdc.gov/nchs/nhanes/continuousnhanes/questionnaires.aspx?BeginYear=2019> (last visited Aug. 16, 2021).

<sup>18</sup> OFFICE OF THE NATIONAL COORDINATOR FOR HEALTH INFORMATION TECHNOLOGY, 2021 INTEROPERABILITY STANDARDS ADVISORY, REFERENCE EDITION (2021), <https://www.healthit.gov/isa/sites/isa/files/inline-files/2021-ISA-Reference-Edition.pdf>.

<sup>19</sup> COMMITTEE ON UNDERSTANDING THE WELL-BEING OF SEXUAL AND GENDER DIVERSE POPULATIONS, *supra* note 13, at 399.

Respectfully Submitted,

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