

May 4, 2022

William N. Parham, III Centers for Medicare & Medicaid Services Office of Strategic Operations and Regulatory Affairs Division of Regulations Development Submitted via *reginfo.gov* 

RE: Agency Information Collection Activities: Submission for OMB Review; Comment Request (CMS-P-0015A) (OMB Control No. 0938-0568)

To Whom It May Concern,

We are grateful for the opportunity to provide comments to the Centers for Medicare and Medicaid Services ("CMS") on its above-captioned notice, which announces its intent to seek approval of revised data collection instruments to be utilized as part of the Medicare Current Beneficiary Survey ("MCBS"). *See* 87 Fed. Reg. 19,517 (April 04, 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 disparities and discrimination experienced 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 in response to the request by CMS for comments on "the necessity and utility of the proposed information collection for the proper performance of the agency's functions . . . [and] ways to enhance the quality, utility, and clarity of the information to be collected[.]" More specifically, we write in support of CMS's inclusion of four socio-demographic items measuring SOGI and eight health equity items about perceived discrimination from health care providers, including on the basis of "gender or gender identity" and sexual orientation, on its proposed revised MCBS questionnaire. In Part I, we briefly review provisions of the Social Security Act related to Medicare, noting that this proposal is consistent with the mission and purposes of CMS and the Medicare program as described therein. In Part II, we provide a review of relevant

<sup>&</sup>lt;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), <a href="https://williamsinstitute.law.ucla.edu/wp-content/uploads/Survey-Measures-Trans-GenIUSS-Sep-2014.pdf">https://williamsinstitute.law.ucla.edu/wp-content/uploads/Survey-Measures-Trans-GenIUSS-Sep-2014.pdf</a>; Sexual Minority Assessment Research Team (SMART), Williams Inst., Best Practices for Asking Questions about Sexual Orientation on Surveys (2009), <a href="https://williamsinstitute.law.ucla.edu/wp-content/uploads/Best-Practices-SO-Surveys-Nov-2009.pdf">https://williamsinstitute.law.ucla.edu/wp-content/uploads/Best-Practices-SO-Surveys-Nov-2009.pdf</a>.

<sup>2</sup> 87 Fed. Reg. at 19,517.

<sup>&</sup>lt;sup>3</sup> WILLIAM S. LONG, OEDA/CMS, SUPPORTING STATEMENT A FOR REVISION OF CURRENTLY APPROVED COLLECTION: MEDICARE CURRENT BENEFICIARY SURVEY (MCBS) 12–13 (2022).

existing research on LGBT people, including on their experiences with discrimination and observed disparities when compared to non-LGBT people—including from studies on the impact of the COVID-19 pandemic—suggesting that information on LGBT Medicare beneficiaries and their experiences would assist CMS in its goal of "supporting innovative approaches to improving quality, accessibility, and affordability in healthcare." 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 CMS and the Medicare Program

As noted by the Department in its accompanying supporting statement, its proposed addition of items measuring SOGI and items about perceived discrimination on the basis of SOGI on the MCBS would "support alignment" with recent executive orders related to equity and the prevention of discrimination.<sup>5</sup> Below, we highlight additional sources of law which support the addition of these proposed items by indicating that the collection and evaluation of a broad range of objective, quality data from beneficiaries is a central component of Congress's intended vision for CMS and its administration of the Medicare program.

For example, CMS, through the Secretary of Health and Human Services ("the Secretary"), maintains a broad grant of authority to issue regulations "as may be necessary to carry out" the various Medicare insurance programs.<sup>6</sup> While the MCBS is not being proposed as part of a regulation here, we note that accompanying said regulatory authority is a requirement that reports be regularly provided to Congress "with respect to the administration of [the Medicare program] and areas of inconsistency or conflict among the various provisions under law and regulation." In setting this requirement, Congress has mandated that said reporting be based on information collected from a number of sources, including "individuals entitled to benefits under part A or enrolled under part B, or both[.]"

Similarly, since the creation of Medicare through the Social Security Amendments of 1965, Congress has imposed on CMS, through the Secretary, a duty to "carry on studies and develop recommendations . . . relating to health care of the aged and the disabled[.]" Congress has directed that these efforts include in part detailing of "the adequacy of existing personnel and facilities for health care" available to beneficiaries under Medicare Parts A and B, alongside identification of "methods for encouraging the further development of efficient and economical

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<sup>&</sup>lt;sup>4</sup> 87 Fed. Reg. at 19,517–18.

<sup>&</sup>lt;sup>5</sup> LONG, *supra* note 3, *citing* Exec. Order 13985, Advancing Racial Equity and Support for Underserved Communities Through the Federal Government, 86 Fed. Reg. 7009 (Jan. 20, 2021) *and* Exec. Order 13988. Preventing and Combating Discrimination on the Basis of Gender Identity or Sexual Orientation, 86 Fed. Reg. 7023 (Jan. 20, 2021).

<sup>&</sup>lt;sup>6</sup> 42 U.S.C. § 1395hh(a)(1).

<sup>&</sup>lt;sup>7</sup> 42 U.S.C. § 1395hh(f)(1).

<sup>&</sup>lt;sup>8</sup> 42 U.S.C. § 1395hh(f)(2)(A).

<sup>&</sup>lt;sup>9</sup> 42 U.S.C. § 1395ll(a).

forms of health care which are a constructive alternative to inpatient hospital care[.]"<sup>10</sup> Likewise, Congress has obligated the Secretary to "evaluate approaches for the collection of data" with respect to the Medicare program, specifically to "allow for the ongoing, accurate, and timely collection and evaluation of data on disparities in health care services and performance on the basis of race, ethnicity, and gender."<sup>11</sup>

Available materials indicate that, to effectuate the congressional mandates described here, CMS administers various data collections, <sup>12</sup> including previous iterations of the MCBS. <sup>13</sup> CMS materials reflect the importance of the MCBS in particular, noting that it "provides important information on Medicare beneficiaries that is not available in CMS administrative data." <sup>14</sup> As described by CMS in its supporting statement, the SOGI-related items it proposes here would fill an "important gap" in the sociodemographic information currently collected through the MCBS, and would help identify instances of "[d]ifferential treatment within the medical community [that are] an important source of inequity that can lead to differences in health outcomes and quality of care." <sup>15</sup> Below, we offer a review of existing research in support of these conclusions.

## II. Research Documents Health Disparities and Discrimination in Health Care Experienced by LGBT People

LGBT-identified people comprise approximately 4.5% of the U.S. adult population. <sup>16</sup> We estimate that approximately 11 million adults in the U.S. identify as LGBT, including approximately 1.4 million adults who are transgender. <sup>17</sup> Estimates on the population of older LGBT adults in the U.S. vary, with some researchers estimating that the population of LGBT people over 50 will double to over 5 million adults by 2030. <sup>18</sup> We estimate that approximately 217,000 transgender adults in the U.S. are age 65 or older. <sup>19</sup>

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

<sup>&</sup>lt;sup>10</sup> *Id*.

<sup>&</sup>lt;sup>11</sup> 42 U.S.C. § 1395b–10(a).

<sup>&</sup>lt;sup>12</sup> See, e.g., SORN 09-70-0500, HHS.GOV, <a href="https://www.hhs.gov/foia/privacy/sorns/09700500/index.html">https://www.hhs.gov/foia/privacy/sorns/09700500/index.html</a> (last accessed Apr. 26, 2022) (noting that CMS's authority to maintain the Health Plan Management System, which "collect[s] and maintain[s] information on Medicare beneficiaries enrolled in Medicare Health Plans," is granted by 42 U.S.C. § 1395ll).

<sup>&</sup>lt;sup>13</sup> About the MCBS, NORC AT THE UNIVERSITY OF CHICAGO <a href="https://mcbs-interactives.norc.org/about/mcbs/">https://mcbs-interactives.norc.org/about/mcbs/</a> (last accessed Apr. 26, 2022).

<sup>&</sup>lt;sup>14</sup> Medicare Current Beneficiary Survey (MCBS), DATA.CMS.GOV, <a href="https://data.cms.gov/medicare-current-beneficiary-survey-mcbs">https://data.cms.gov/medicare-current-beneficiary-survey-mcbs</a> (last accessed Apr. 26, 2022).

<sup>&</sup>lt;sup>15</sup> Long, *supra* note 3.

<sup>&</sup>lt;sup>16</sup> KERITH J. CONRON & SHOSHANA K. GOLDBERG, WILLIAMS INST., ADULT LGBT POPULATION IN THE UNITED STATES 1 (2020), <a href="https://williamsinstitute.law.ucla.edu/wp-content/uploads/LGBT-Adult-US-Pop-Jul-2020.pdf">https://williamsinstitute.law.ucla.edu/wp-content/uploads/LGBT-Adult-US-Pop-Jul-2020.pdf</a>.

<sup>17</sup> Id

<sup>&</sup>lt;sup>18</sup> Soon Kyu Choi & Ilan H. Meyer, Williams Inst., LGBT Aging: A Review of Research Findings, Needs, and Policy Implications 2 (2016), <a href="https://williamsinstitute.law.ucla.edu/wp-content/uploads/LGBT-Aging-Aug-2016.pdf">https://williamsinstitute.law.ucla.edu/wp-content/uploads/LGBT-Aging-Aug-2016.pdf</a>.

<sup>&</sup>lt;sup>19</sup> Andrew R. Flores et al., Williams Inst., How Many Adults Identify as Transgender in the United States? 5 (2016), <a href="https://williamsinstitute.law.ucla.edu/wp-content/uploads/Trans-Adults-US-Aug-2016.pdf">https://williamsinstitute.law.ucla.edu/wp-content/uploads/Trans-Adults-US-Aug-2016.pdf</a>.

between 2015 and 2017, we've previously estimated that 58% of LGBT adults are female.<sup>20</sup> Similarly, we estimate that 21% of LGBT adults identify as Latino/a or Hispanic, 12% as Black, and 5% as more than one race.<sup>21</sup>

A longstanding body of research reflects that LGBT people report experiences with public and private discrimination in the United States, as well as health and other disparities when compared to their non-LGBT peers that are often related to their SOGI and such experiences with discrimination and other forms of stigma. This research includes accounts of LGBT individuals' experiences with discrimination when attempting to access health care. However, we note a dearth of research on their experiences accessing care as Medicare beneficiaries specifically, given the lack of items allowing for the identification of LGBT populations in existing information collections administered by CMS.

In *Obergefell v. Hodges*, the Supreme Court observed that gay men and lesbians have been "prohibited from most government employment, barred from military service, excluded under immigration laws, targeted by police, and burdened in their rights to associate." The Seventh Circuit has similarly explained that "homosexuals are among the most stigmatized, misunderstood, and discriminated-against minorities in the history of the world[.]" And with respect to transgender people, the District of Columbia Court of Appeals has observed that "[t]he hostility and discrimination that transgender individuals face in our society today is well-documented." While social acceptance and the legal rights of LGBT people in the United States have generally improved over the past few decades (in some places more than others), ample research confirms that anti-LGBT stigma and discrimination remain widespread, and that certain disparities only continue to widen, in particular when factoring in the compounding effects of discrimination faced along intersectional dimensions of race, ethnicity, and sex, alongside SOGI. Below, we offer a brief review of available research relevant to the proposed items, focusing on studies on LGBT older adults where possible.

Williams Institute research has shown that LGBT older adults face unique challenges within the context of aging compared to their cisgender, heterosexual peers, including reporting worse mental and physical health outcomes; barriers to receiving formal and informal health care and social support; and experiences of discrimination based on SOGI.<sup>25</sup> Such experiences with discrimination include incidents of overt homophobia or transphobia by health care providers, leading some to delay or avoid obtaining care, or otherwise conceal their SOGI from providers, for fear of discrimination.<sup>26</sup> Recent studies suggest this fear remains salient among LGBT people; for example, among respondents to our NIH-funded Generations and TransPop studies on sexual and gender minority people, respectively, one-third of sexual minorities and almost

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<sup>&</sup>lt;sup>20</sup> LGBT Demographic Data Interactive, WILLIAMS INST. (January 2019), <a href="https://williamsinstitute.law.ucla.edu/visualization/lgbt-stats/?topic=LGBT#demographic.">https://williamsinstitute.law.ucla.edu/visualization/lgbt-stats/?topic=LGBT#demographic.</a>
<sup>21</sup> Id

<sup>&</sup>lt;sup>22</sup> 135 S. Ct. 2584, 2596 (2015).

<sup>&</sup>lt;sup>23</sup> Baskin v. Bogan, 766 F.3d 648, 663 (7<sup>th</sup> Cir. 2014); *see also* Windsor v. United States, 699 F.3d 169, 182 (2d Cir. 2012) ("It is easy to conclude that homosexuals have suffered a history of discrimination."), *aff'd*, 570 U.S. 744 (2013).

<sup>&</sup>lt;sup>24</sup> Brocksmith v. United States, 99 A.3d 690, 698 n.8 (D.C. 2014).

<sup>&</sup>lt;sup>25</sup> CHOI & MEYER, *supra* note 18, at 0–1.

<sup>&</sup>lt;sup>26</sup> *Id*. at 7.

two-thirds of transgender people reported worrying about being negatively judged in interactions with a health care provider.<sup>27</sup> Additionally, these findings are consistent with our and others' research on LGBT adults' health more broadly, including a wide range of studies utilizing data collected through the National Health Interview Survey, which began measuring respondents' sexual orientation in 2013.<sup>28</sup>

Existing research suggests that the health disparities observed when comparing LGBT older adults to their non-LGBT counterparts are particularly pronounced for those who are transgender. These findings include higher rates of internalized stigma and suicidal ideation among transgender people, even when compared to their cisgender LGB peers.<sup>29</sup> Transgender older adults also often encounter unique challenges related to health care access beyond those reported by cisgender LGB older adults, as their population "may seek more frequent and intimate health care due to age related physical conditions and disabilities."<sup>30</sup>

Such poorer health outcomes are likely influenced in part by LGBT populations' experiences with economic insecurity, including reports of higher poverty rates among LGBT people across the life course.<sup>31</sup> Similarly, Williams Institute research has noted high rates of food insecurity among all LGBT people,<sup>32</sup> including evidence of particular vulnerabilities for LGBT older adults.<sup>33</sup> Our research suggests that among LGBT people, transgender people are disproportionately likely to experience certain forms of economic insecurity like they are certain negative health outcomes: for example, data collected between 2016 and 2019 show that 8% of transgender people experienced homelessness within the prior year, compared to 3% of cisgender

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<sup>&</sup>lt;sup>27</sup> 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 27 (2021), https://williamsinstitute.law.ucla.edu/wp-content/uploads/Generations-TransPop-Toplines-Jun-2021.pdf.

<sup>&</sup>lt;sup>28</sup> Williams Institute Scholars, Comment Letter on Review of the National Health Interview Survey (June 15, 2020), <a href="https://williamsinstitute.law.ucla.edu/wp-content/uploads/Comment-NHIS-Jun-2020.pdf">https://williamsinstitute.law.ucla.edu/wp-content/uploads/Comment-NHIS-Jun-2020.pdf</a>. A table documenting many of these studies is included as an appendix to *id*.

<sup>&</sup>lt;sup>29</sup> CHOI & MEYER, *supra* note 18, at 3.

<sup>&</sup>lt;sup>30</sup> *Id.* at 8.

<sup>&</sup>lt;sup>31</sup> M.V. LEE BADGETT ET AL., WILLIAMS INST., LGBT POVERTY IN THE UNITED STATES: A STUDY OF DIFFERENCES BETWEEN SEXUAL ORIENTATION AND GENDER IDENTITY GROUPS 14–15 (2019), <a href="https://williamsinstitute.law.ucla.edu/wp-content/uploads/National-LGBT-Poverty-Oct-2019.pdf">https://williamsinstitute.law.ucla.edu/wp-content/uploads/National-LGBT-Poverty-Oct-2019.pdf</a>. While our study found that poverty rates were higher for LGBT people when compared to non-LGBT people across every age group including those over age 65, the observed differences were only statistically significant among people aged 18 to 44 years old. *Id.* 

years old. *Id.*32 Kerith J. Conron et al., Williams Inst., Food Insufficiency Among LGBT Adults During the COVID-19 Pandemic (2022), <a href="https://williamsinstitute.law.ucla.edu/wp-content/uploads/LGBT-Food-Insufficiency-Apr-2022.pdf">https://williamsinstitute.law.ucla.edu/wp-content/uploads/LGBT-Food-Insufficiency-Apr-2022.pdf</a>; Kerith J. Conron & Kathryn K. O'Neill, Williams Inst., Food Insufficiency Among Transgender Adults During the COVID-19 Pandemic, <a href="https://williamsinstitute.law.ucla.edu/wp-content/uploads/Trans-Food-Insufficiency-Update-Apr-2022.pdf">https://williamsinstitute.law.ucla.edu/wp-content/uploads/Trans-Food-Insufficiency-Update-Apr-2022.pdf</a>; Bianca D.M. Wilson & Kerith J. Conron, Williams Inst., National Estimates of Food Insecurity: LGBT People and COVID-19 (2020), <a href="https://williamsinstitute.law.ucla.edu/wp-content/uploads/Food-Insecurity-COVID19-Apr-2020.pdf">https://williamsinstitute.law.ucla.edu/wp-content/uploads/Food-Insecurity-COVID19-Apr-2020.pdf</a>; Taylor N.T. Brown et al., Williams Inst., Food Insecurity and SNAP Participation in the LGBT Community (2016), <a href="https://williamsinstitute.law.ucla.edu/wp-content/uploads/Food-Insecurity-SNAP-July-2016.pdf">https://williamsinstitute.law.ucla.edu/wp-content/uploads/Food-Insecurity-SNAP-July-2016.pdf</a>.

<sup>&</sup>lt;sup>33</sup> See, e.g., BIANCA D.M. WILSON ET AL., WILLIAMS INST., "WE'RE STILL HUNGRY" LIVED EXPERIENCES WITH FOOD INSECURITY AND FOOD PROGRAMS AMONG LGBTQ PEOPLE 18 (2020), <a href="https://williamsinstitute.law.ucla.edu/wp-content/uploads/LGBTQ-Food-Bank-Jun-2020.pdf">https://williamsinstitute.law.ucla.edu/wp-content/uploads/LGBTQ-Food-Bank-Jun-2020.pdf</a> (noting the majority of discussions on the use of food banks to manage food insecurity were among respondents age 50 and older).

LGB people and 1% of non-LGBT people.<sup>34</sup> In accordance with these findings, in a recent study on California, we found that transgender adults were significantly more likely than cisgender adults to report being covered by Medi-Cal or other public health insurance; while transgender adults in this study were less likely to report being covered by Medicare specifically, this may be explained at least in part by the transgender population in California skewing younger.<sup>35</sup>

Data collected prior to the COVID-19 pandemic suggest that transgender older adults are likely disproportionately vulnerable to experiencing negative health outcomes associated with same. We previously estimated that, across the U.S., 137,600 transgender people lack health insurance; 450,000 transgender people had not gone to a doctor in the past year because they could not afford it; and 319,800 transgender adults had one or more medical conditions putting them at increased risk of serious illness related to COVID-19, including asthma, diabetes, heart disease, and HIV.<sup>36</sup> A separate report highlighting health vulnerabilities among LGBT older adults in California found that a significant number of LGBT people in the state are age 65 and older—an estimated 162,000 LGB and 9,000 transgender people at the time—many of whom also suffer from asthma, heart disease, and diabetes.<sup>37</sup>

Our recent research on the impact of the COVID-19 pandemic on U.S. adults also suggests that LGBT adults, particularly LGBT people of color and gender minority people, have been disproportionately experiencing its negative economic effects, 38 which may in turn be impacting their health outcomes. For example, in a study on people ages 45 and older, we found that LGBT respondents—particularly LGBT respondents of color—were more likely to report job loss, problems affording basic household goods, and other negative economic impacts related to COVID-19 than older non-LGBT respondents. While our study found that a greater percentage of older LGBT people of color had tested positive for COVID-19 when compared to older White LGBT people, these differences were not statistically significant. Nonetheless,

<sup>&</sup>lt;sup>34</sup> BIANCA D.M. WILSON ET AL., WILLIAMS INST., HOMELESSNESS AMONG LGBT ADULTS IN THE US 1 (2020), <a href="https://williamsinstitute.law.ucla.edu/wp-content/uploads/LGBT-Homelessness-May-2020.pdf">https://williamsinstitute.law.ucla.edu/wp-content/uploads/LGBT-Homelessness-May-2020.pdf</a>.

<sup>&</sup>lt;sup>35</sup> Susan H. Babey, Joelle Wolstein, Jody L. Herman & Bianca D.M. Wilson, UCLA Ctr. for Health Pol'y Res. & Williams Inst., Gaps in Health Care Access and Health Insurance Among LGBT Populations in California 5 (2022), <a href="https://williamsinstitute.law.ucla.edu/publications/gaps-health-care-lgbt-ca">https://williamsinstitute.law.ucla.edu/publications/gaps-health-care-lgbt-ca</a>.

<sup>&</sup>lt;sup>36</sup> JODY L. HERMAN & KATHRYN O'NEILL, WILLIAMS INST., VULNERABILITIES TO COVID-19 AMONG TRANSGENDER ADULTS IN THE U.S. 1–2 (2020), <a href="https://williamsinstitute.law.ucla.edu/wp-content/uploads/Trans-COVID19-Apr-2020.pdf">https://williamsinstitute.law.ucla.edu/wp-content/uploads/Trans-COVID19-Apr-2020.pdf</a>.

<sup>&</sup>lt;sup>37</sup> ILAN H. MEYER & SOON KYU CHOI, WILLIAMS INST., VULNERABILITIES TO COVID-19 AMONG OLDER LGBT ADULTS IN CALIFORNIA 1–2 (2020), <a href="https://williamsinstitute.law.ucla.edu/wp-content/uploads/Older-LGB-COVID-CA-Apr-2020.pdf">https://williamsinstitute.law.ucla.edu/wp-content/uploads/Older-LGB-COVID-CA-Apr-2020.pdf</a>.

<sup>&</sup>lt;sup>38</sup> See also Thom File & Joey Marshall, Household Pulse Survey Shows LGBT Adults More Likely to Report Living in Households With Food and Economic Insecurity Than Non-LGBT Respondents, U.S. CENSUS BUREAU, <a href="https://www.census.gov/library/stories/2021/08/lgbt-community-harder-hit-by-economic-impact-of-pandemic.html">https://www.census.gov/library/stories/2021/08/lgbt-community-harder-hit-by-economic-impact-of-pandemic.html</a> (noting the U.S. Census Bureau's similar findings, based on data collected during the first waves of the Household Pulse Survey that included SOGI measures).

<sup>&</sup>lt;sup>39</sup> CHRISTY MALLORY, BRAD SEARS & ANDREW R. FLORES, WILLIAMS INST., COVID-19 AND LGBT ADULTS AGES 45 AND OLDER IN THE US 2–3 (2021), <a href="https://williamsinstitute.law.ucla.edu/wp-content/uploads/COVID-LGBT-45-May-2021.pdf">https://williamsinstitute.law.ucla.edu/wp-content/uploads/COVID-LGBT-45-May-2021.pdf</a>.

<sup>&</sup>lt;sup>40</sup> *Id.* at 10 (noting that among those reporting being tested "12.8% of older LGBT people of color and 5.5% of older white LGBT people tested positive. . . . Older non-LGBT people of color (9.4%) and older white non-LGBT people (6.5%) tested positive at similar rates.").

these findings suggest a continued need for quality, representative data that would allow for additional investigation into the impacts of the pandemic by CMS and researchers.<sup>41</sup>

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

In light of this body of research, we commend CMS for including the collection of information on beneficiaries' SOGI and their experiences with perceived discrimination based on SOGI within its proposed revised MCBS questionnaire. As described by CMS, these items would allow for the collection of "nationally representative data on topics such as the accessibility and utilization of health care services by [LGBT] populations and the resulting health disparities that impact this community[,]"42 consistent with the mission and purposes of the Medicaid program as described here. And, notably CMS's proposed items measuring SOGI are consistent with our expertise on best practices for doing so in the context of population-based surveys; 43 the existing practices of other federal agencies; and recent recommendations from an ad hoc panel formed by the National Academies of Sciences, Engineering, and Medicine on SOGI-related methodological issues (the "NASEM Panel"). 44

Questions measuring sexual orientation have been included on federal surveys for over two decades, 45 including in large-scale, population-based surveys administered by the Centers for Disease Control and Prevention. 46 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. 47 The federal government has long engaged in its own review of best practices for the measurement of SOGI, 48 with research on federal implementations of SOGI measures suggesting that respondents are unlikely to consider SOGI information to be particularly sensitive, and

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<sup>&</sup>lt;sup>41</sup> ANDREW BURWICK ET AL., MATHEMATICA POLICY RESEARCH, HUMAN SERVICES FOR LOW-INCOME AND AT-RISK LGBT POPULATIONS: AN ASSESSMENT OF THE KNOWLEDGE BASE AND RESEARCH NEEDS 19 (2014) (advising that "data from federal and state surveys with large population-based samples are needed to develop findings that are representative of the LGBT population at the state or national level and to generate sample sizes large enough to explore the characteristics and experiences of LGBT subpopulations defined by sexual orientation, gender identity, race/ethnicity, and other characteristics.").

<sup>&</sup>lt;sup>42</sup> LONG, *supra* note 3, at 14.

<sup>&</sup>lt;sup>43</sup> WILLIAMS INSTITUTE SCHOLARS, SEXUAL ORIENTATION AND GENDER IDENTITY (SOGI) ADULT MEASURES RECOMMENDATIONS FAQS (2020), <a href="https://williamsinstitute.law.ucla.edu/wp-content/uploads/SOGI-Measures-FAQ-Mar-2020.pdf">https://williamsinstitute.law.ucla.edu/wp-content/uploads/SOGI-Measures-FAQ-Mar-2020.pdf</a>.

<sup>&</sup>lt;sup>44</sup> Measuring Sex, Gender Identity, and Sexual Orientation for the National Institutes of Health, NAT'L ACADEMIES OF SCIENCES, ENGINEERING, & MED., <a href="https://www.nationalacademies.org/our-work/measuring-sex-gender-identity-and-sexual-orientation-for-the-national-institutes-of-health">https://www.nationalacademies.org/our-work/measuring-sex-gender-identity-and-sexual-orientation-for-the-national-institutes-of-health</a> (last visited Apr. 6, 2022).

<sup>&</sup>lt;sup>45</sup> 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), <a href="https://cpb-us-el.wpmucdn.com/sites.northwestern.edu/dist/3/817/files/2017/01/">https://cpb-us-el.wpmucdn.com/sites.northwestern.edu/dist/3/817/files/2017/01/</a> WorkingGroupPaper1 CurrentMeasures 08-16-1xnai8d.pdf.

<sup>&</sup>lt;sup>46</sup> 2019 BRFSS Survey Data and Documentation, CDC.GOV (Aug. 31, 2020), <a href="https://www.cdc.gov/brfss/annual\_data/annual\_2019.html">https://www.cdc.gov/brfss/annual\_data/annual\_2019.html</a>; Questionnaires | YBRS, CDC.GOV (Nov. 17, 2020), <a href="https://www.cdc.gov/healthyyouth/data/yrbs/questionnaires.htm">https://www.cdc.gov/healthyyouth/data/yrbs/questionnaires.htm</a>.

<sup>&</sup>lt;sup>47</sup> Williams Institute Scholars, Comment Letter on Proposed Basic Demographic Items for the Current Population Survey (March 22, 2021), <a href="https://williamsinstitute.law.ucla.edu/wp-content/uploads/Comment-NHIS-Jun-2020.pdf">https://williamsinstitute.law.ucla.edu/wp-content/uploads/Comment-NHIS-Jun-2020.pdf</a>. <a href="https://www.ucla.edu/wp-content/uploads/Comment-NHIS-Jun-2020.pdf">https://williamsinstitute.law.ucla.edu/wp-content/uploads/Comment-NHIS-Jun-2020.pdf</a>. <a href="https://www.ucla.edu/wp-content/uploads/Comment-NHIS-Jun-2020.pdf">https://williamsinstitute.law.ucla.edu/wp-content/uploads/Comment-NHIS-Jun-2020.pdf</a>. <a href="https://www.ucla.edu/wp-content/uploads/Comment-NHIS-Jun-2020.pdf">https://williamsinstitute.law.ucla.edu/wp-content/uploads/Comment-NHIS-Jun-2020.pdf</a>. <a href="https://www.ucla.edu/wp-content/uploads/Comment-NHIS-Jun-2020.pdf">https://williamsinstitute.law.ucla.edu/wp-content/uploads/Comment-NHIS-Jun-2020.pdf</a>. <a href="https://www.ucla.edu/wp-content/uploads/Comment-NHIS-Jun-2020.pdf">https://www.ucla.edu/wp-content/uploads/Comment-NHIS-Jun-2020.pdf</a>. <a href="https://www.ucla.edu/wp-cont

would therefore provide such information if asked.<sup>49</sup> Similarly, studies suggest that sexual minority people are not a population that is difficult to survey.<sup>50</sup>

As CMS is aware,<sup>51</sup> the NASEM Panel's recommended measures were outlined in a recently released consensus study report offering guidance and best practices for collecting data on SOGI, as well as on variations in sex characteristics, in population-based surveys and other settings.<sup>52</sup> 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.<sup>53</sup> 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;<sup>54</sup> have undergone extensive testing; and have been observed to improve the "overall measurement quality" of studies.<sup>55</sup>

As scholars with experience in measurement development and testing, we would recommend that CMS 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 CMS ensure that the data contemplated here are collected and reported using all appropriate privacy standards. All entities responsible for 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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<sup>&</sup>lt;sup>49</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), <a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4157837/pdf/pone.0107104.pdf">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4157837/pdf/pone.0107104.pdf</a>.

<sup>&</sup>lt;sup>50</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.

<sup>&</sup>lt;sup>51</sup> LONG, *supra* note 3, at 14.

<sup>&</sup>lt;sup>52</sup> NAT'L ACADEMIES OF SCIENCES, ENGINEERING, & MED., MEASURING SEX, GENDER IDENTITY, AND SEXUAL ORIENTATION (2022), <a href="https://nap.nationalacademies.org/catalog/26424/measuring-sex-gender-identity-and-sexual-orientation">https://nap.nationalacademies.org/catalog/26424/measuring-sex-gender-identity-and-sexual-orientation</a>.

<sup>&</sup>lt;sup>53</sup> *Id.* at S-4.

<sup>&</sup>lt;sup>54</sup> 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), <a href="https://www.census.gov/library/stories/2021/08/household-pulse-survey-updates-sex-question-now-asks-sexual-orientation-and-gender-identity.html">https://www.census.gov/library/stories/2021/08/household-pulse-survey-updates-sex-question-now-asks-sexual-orientation-and-gender-identity.html</a>.

<sup>&</sup>lt;sup>55</sup> NAT'L ACADEMIES OF SCIENCES, ENGINEERING, & MED., *supra* note 52, at S-6, 5-9.

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