

August 7, 2023

Office of Information and Regulatory Affairs  
Office of Management and Budget  
New Executive Building  
725 17th St. NW, Room 10235  
Washington, DC 20503

Re: Agency Information Collection Activities; Submission for OMB Review; Public Comment Request; SHIP-SMP Survey of One-on-One Assistance, (OMB Control Number 0985-0057)

Dear Office of Management and Budget Desk Officer for the Administration for Community Living,

On behalf of the undersigned 3 organizations committed to advancing the health and well-being of LGBTQI+ people in the United States, we write to voice our support for the Administration for Community Living (ACL) adding sexual orientation and gender identity measures to the Survey of One-on-One Assistance provided by the State Health Insurance Assistance Program (SHIP) or Senior Medicare Patrol (SMP) program (88 FR 43357).<sup>1</sup> We support these proposals, which represent important steps in data collection to advance equity on the basis of sexual orientation, gender identity and sex characteristics (SOGISC). We also offer recommendations for implementation of the proposed measures, and encourage ACL to work toward collecting data on variations in sex characteristics.

### **The importance of improving SOGISC data collection through the SOOA**

The Survey of One-on-One Assistance (SOOA) collects important data on beneficiaries who meet with team members from SHIP-SMP programs. The SHIP program helps Medicare beneficiaries understand their benefits and options, coverage rules, written notices and forms, appeal rights and procedures, with grantees providing free, in-depth, unbiased, one-on-one health insurance counseling and assistance to beneficiaries, their families, and caregivers.<sup>2</sup> The SMP program aims to empower and assist Medicare beneficiaries, their families, and caregivers to prevent, detect, and report suspected healthcare fraud, errors, and abuse, with grantees providing one-on-one assistance and serving as consumer advocates to resolve billing issues as

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<sup>1</sup> Administration for Community Living, "Agency Information Collection Activities; Submission for OMB Review; Public Comment Request; SHIP-SMP Survey of One-on-One Assistance, (OMB Control Number 0985-0057)" *Federal Register* 88 (129) (2023): 2023-14336, available at <https://www.federalregister.gov/documents/2023/07/07/2023-14336/agency-information-collection-activities-submission-for-omb-review-public-comment-request-ship-smp>

<sup>2</sup> Administration for Community Living, "State Health Insurance Assistance Program," available at <https://acl.gov/programs/connecting-people-services/state-health-insurance-assistance-program-ship> (last accessed July 2023)

needed.<sup>3</sup> These programs are critical to ensure beneficiaries – including those with limited incomes, Medicare beneficiaries under the age of 65 with disabilities, and individuals dually eligible for Medicare and Medicaid – make informed decisions about their benefits and successfully navigate program processes to access care. In 2018, SHIP grantees provided one-on-one health insurance counseling to more than 2,694,135 Medicare beneficiaries, their families, and caregivers, and in 2021 SMP projects hosted more than 239,625 one-on-one counseling sessions with, or on behalf of Medicare beneficiaries regarding potential fraud, error, or abuse.<sup>4</sup>

Data collected on the SOOA are used to gauge individuals’ satisfaction with services provided by SHIP-SMP team members, assess the quality and effectiveness of these programs, and determine whether beneficiaries are receiving accurate, relevant, and timely information.<sup>5</sup> These data offer valuable insight on how SHIP-SMP programs can be improved to provide better services to their target population. However, the current lack of SOGISC measures on the SOOA leaves the experiences of LGBTQI+ beneficiaries invisible. Research shows that LGBTQI+ older adults are racially and ethnically diverse and are more likely to experience economic insecurity compared to other older adults.<sup>6</sup> Given the importance of Medicare in supporting older adults as they age, deepening our knowledge of the needs and experiences of LGBTQI+ beneficiaries, especially those from diverse communities, is paramount.

Collecting SOGISC data, including through the SOOA, is critical to better comprehend the experiences and needs of LGBTQI+ Medicare beneficiaries interacting with SHIP-SMP programs and grantees. For example, SHIP program grantees may help same-sex couple beneficiaries better understand how marriage impacts their Medicare rights<sup>7</sup> or transgender beneficiaries better understand Medicare coverage of medically necessary gender-affirming surgeries, prescription drugs related to transition care, and their right to nondiscrimination in health care

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<sup>3</sup> Administration for Community Living, “Senior Medicare Patrol,” available at <https://acl.gov/programs/protecting-rights-and-preventing-abuse/senior-medicare-patrol-smp> (last accessed July 2023)

<sup>4</sup> Administration for Community Living, “State Health Insurance Assistance Program,” available at <https://acl.gov/programs/connecting-people-services/state-health-insurance-assistance-program-ship> (last accessed July 2023); Administration for Community Living, “Senior Medicare Patrol,” available at <https://acl.gov/programs/protecting-rights-and-preventing-abuse/senior-medicare-patrol-smp> (last accessed July 2023).

<sup>5</sup> Office of Management and Budget, “SHIP-SMP Survey of One-on-One Assistance,” available at <https://omb.report/omb/0985-0057> (last accessed August 2023)

<sup>6</sup> Cantave, Cassandra. *Dignity 2022: The Experience of LGBTQ Older Adults*. Washington, DC: AARP Research, June 2022. <https://doi.org/10.26419/res.00549.001>

<sup>7</sup> Justice In Aging, “Marriage, Medicare, & Medicaid: What Same-Sex Couples Need to Know,” available at <https://justiceinaging.org/wp-content/uploads/2023/01/SAGE-SHIP-Marriage-Medicare-Medicaid-Final.pdf> (last accessed July 2023)

under the law.<sup>8</sup> Given the direct provision of services and personalized nature of one-on-one sessions, it is especially important to ensure SHIP-SMP grantees offer relevant information in a culturally competent manner and that the privacy and confidentiality of respondent information and their feedback is preserved. Respondents should be notified that they may receive a survey afterwards so that they can provide feedback to improve the program, but that their responses will be de-identified and treated with privacy and confidentiality.

ACL's current proposal to add sexual orientation and gender identity (SOGI) measures to the SOOA for SHIP-SMP programs is an essential step forward to collect information about the accessibility and utilization of ACL services by LGBTQI+ populations, identify health disparities, and determine whether the information provided meets the needs of LGBTQI+ beneficiaries. Insights gained by adding SOGI measures should be used to improve SHIP-SMP program design and service delivery and result in more appropriate Medicare choices for LGBTQI+ beneficiaries. We agree with ACL's assertion that these data may also support overall agency improvements related to reallocation of resources, revisions to agency processes and policies, and/or the development of guidance related to the agency's customer service.<sup>9</sup>

### **Adding SOGI measures to the SOOA will help to advance equity for LGBTQI+ communities**

Lack of routine, standardized collection of demographic data on sexual orientation, gender identity, and variations in sex characteristics poses a barrier to researchers, advocates, and policymakers to identify and address health disparities and the social determinants that drive them in order to advance equity for LGBTQI+ communities.<sup>10</sup> The absence of these demographic measures on many federal statistical surveys results in evidence gaps about LGBTQI+ communities that must be addressed to better understand the experiences and needs of these populations, so they can be better reflected in government policies, programs, funding investments, and enforcement of civil rights laws.

We therefore applaud ACL's proposal to add SOGI measures to the SOOA and its cross-agency policy to collect sexual orientation and gender identity demographic data in all information collection requests where other demographic information is collected for purposes other than program eligibility.<sup>11</sup> These policies reflect the U.S. Department of Health and Human Services' ongoing commitment to advancing the rights of LGBTQI+ communities and to adopting a data-driven approach to policymaking.<sup>12</sup>

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<sup>8</sup> Justice in Aging, "Medicare and Transgender Older Adults," available at <https://www.lgbtagingcenter.org/resources/pdfs/SAGE%20SHIP%20Medicare%20and%20Trans%20Older%20Adults%20Final%20R1.pdf> (last accessed July 2023)

<sup>9</sup> Office of Management and Budget, "SHIP-SMP Survey of Group Outreach and Education Events," available at [https://omb.report/omb/0985-0056#google\\_vignette](https://omb.report/omb/0985-0056#google_vignette) (last accessed July 2023)

<sup>10</sup> National Academies of Sciences, Engineering, and Medicine, *Understanding the Well-Being of LGBTQI+ Populations*, 371-372 (2020), <https://doi.org/10.17226/25877>

<sup>11</sup> Office of Management and Budget, "ACL SOGI Data Collection Policy," available at <https://omb.report/icr/202306-0985-001/doc/133679600> (last accessed July 2023)

<sup>12</sup> For example, see U.S. Department of Health and Human Services, "HHS Announces Prohibition on Sex Discrimination Includes Discrimination on the Basis of Sexual Orientation and Gender Identity," Press release, May

Taking these actions also aligns with the Biden-Harris Administration’s dedication to adopting a whole-of-government approach to further equity for LGBTQI+ and other underserved communities through various actions, including but not limited to expanding data collection efforts. For example, Executive Order 13985<sup>13</sup> and Executive Order 14075<sup>14</sup> require the implementation of comprehensive policies to improve the federal government’s ability to advance the collection of SOGISC data, in order to build evidence and leverage data to advance equity for LGBTQI+ people. By adding SOGI measures to the SOOA the ACL will help answer questions posed in the Learning Agenda of the Federal Evidence Agenda on LGBTQI+ Equity required by Executive Order 14075, such as “Which federal programs and policies advance equitable access of culturally and clinically competent health care to various vulnerable subpopulations, such as LGBTQI+ older adults?”<sup>15</sup> and “To what extent do LGBTQI+ older adults experience disparate access to benefits and services?”<sup>16</sup>

### **Support for the proposed measures and recommendations for future data collection**

We strongly support ACL’s proposed SOGI measures for the SHIP-SMP SOOA,<sup>17</sup> which reflect several recommendations from the National Academies of Science, Engineering, and Medicine’s recently published report on measuring sex, gender identity, and sexual orientation.<sup>18</sup> This consensus report provides a comprehensive review of methodological evidence, best practices, and recommended measures for collecting SOGISC data on sexual orientation, gender identity, and variations in sex characteristics (SOGISC).

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10, 2021, available at

<https://www.hhs.gov/about/news/2021/05/10/hhs-announces-prohibition-sex-discriminationincludes-discrimination-basis-sexual-orientation-gender-identity.html>; Advancing LGBT Health & Well-being: 2016 Report, HHS LGBT Policy Coordinating Committee, U.S. Department of Health and Human Services, available at <https://www.hhs.gov/programs/topic-sites/lgbtqi/reports/health-objectives-2016.html>

See Objective 4.4: Improve Data Collection, HHS Strategic Plan FY 2022-2026, U.S. Department of Health and Human Services, <https://healthapiguy.substack.com/p/the-scheduling-conundrum?s=r>

<sup>13</sup> Executive Office of the President, “Advancing Racial Equity and Support for Underserved Communities Through the Federal Government,” *Federal Register* 86 (14) (2021): 7009-7013, available at <https://www.govinfo.gov/content/pkg/FR-2021-01-25/pdf/2021-01753.pdf>

<sup>14</sup> Executive Office of the President, “Advancing Equality for Lesbian, Gay, Bisexual, Transgender, Queer, and Intersex Individuals,” *Federal Register* 87 (118) (2022): 37189-37195, available at <https://www.federalregister.gov/documents/2022/06/21/2022-13391/advancing-equality-for-lesbian-gay-bisexual-transgender-queer-and-intersex-individuals>

<sup>15</sup> Subcommittee on Sexual Orientation, Gender Identity, and Variations in Sex Characteristics (SOGI) Data Subcommittee on Equitable Data, “Federal Evidence Agenda on LGBTQI+ Equity,” available at <https://www.whitehouse.gov/wp-content/uploads/2023/01/Federal-Evidence-Agenda-on-LGBTQI-Equity.pdf> at pg. 21

<sup>16</sup> Ibid. at pg. 27

<sup>17</sup> Office of Management and Budget, “ACL SOGI Data Collection Policy,” available at <https://omb.report/icr/202306-0985-001/doc/133679600> (last accessed July 2023)

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<https://www.nationalacademies.org/our-work/measuring-sex-gender-identity-and-sexual-orientation-for-the-national-institutes-of-health>

Notably, that report also recommended testing and fielding measures of variations in sex characteristics that can identify intersex populations. Like other sexual and gender minorities, there is a growing body of evidence that people with intersex traits experience stigma, discrimination, and barriers to care and services, and experience disparities in health and levels of disability, and potentially in other areas such as education and employment, compared to the general population as a result. Yet data collection on people with intersex traits remains extremely limited.<sup>19</sup> While most existing research focuses on intersex children, adolescents, and young adults,<sup>20</sup> even less is known about how discrimination and stigma affect intersex adults across the lifespan, especially older adults, but what is known points to continuing disparities and unmet needs.<sup>21 22</sup> We encourage ACL to invest in additional research and testing of a measure of variations in sex characteristics for this and other ACL surveys, based on recommendations laid out in the National Academies report. We also encourage ACL to coordinate on an ongoing basis with other agencies such as the Centers for Disease Control and Prevention and the Census Bureau, to identify and leverage opportunities and best practices to advance the collection of intersex-inclusive data.

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<sup>19</sup> See, e.g., Medina, C., and Mahowald, L., *Discrimination and Barriers to Well-Being: The State of the LGBTQI+ Community in 2022*, Center for American Progress (2023), <https://www.americanprogress.org/article/discrimination-and-barriers-to-well-being-the-state-of-the-lgbtqi-community-in-2022>; Caroline Medina and Lindsay Mahowald, "Key Issues Facing People With Intersex Traits," Center for American Progress (2021), <https://www.americanprogress.org/article/key-issues-facing-people-intersex-traits/>; National Academies of Sciences, Engineering, and Medicine, *Understanding the Well-Being of LGBTQI+ Populations*, 371-372 (2020), <https://doi.org/10.17226/25877>; Amy Rosenwohl-Mack et al, "A National Study on the Physical and Mental Health of Intersex Adults in the U.S.," 15 *PLoS ONE* e0240088 (2020). See also European Union Fundamental Rights Agency, *EU-LGBTI II: A long way to go for LGBTI equality* (2020), <https://fra.europa.eu/en/publication/2020/eu-lgbti-survey-results>; World Bank Group, Williams Instit. et al., *Life on the Margins: Survey Results of the Experiences of LGBTI People in Southeastern Europe* (2018), <https://openknowledge.worldbank.org/handle/10986/30607>; Jones, T., et al., *Intersex: Stories and Statistics from Australia* 146-47 (2016).

<sup>20</sup> See, e.g., The Trevor Project, *The Mental Health and Well-being of LGBTQ Youth who are Intersex* (2021), available at: <https://www.thetrevorproject.org/wp-content/uploads/2021/12/Intersex-Youth-Mental-Health-Report.pdf>; Mandy Henningham & Tiffany Jones, *Intersex students, sex-based relational learning & isolation*, *Sex Educ.* (2021); Tiffany Jones, *The needs of students with intersex variations*, 16 *Sex Educ.* 602 (2016).

<sup>21</sup> A.W. Berry & S. Munro, *Aging in obscurity: a critical literature review regarding older intersex people*, *Sex Reprod Health Matters* 30(1):2136027 (2022); J. Latham & C. Barrett, *Appropriate bodies and other damn lies*, *Australasian Journal on Ageing*, 34: 19-20 (2015); J. Latham & C. Barrett, "As we age": *An Evidence-based Guide to Intersex Inclusive Aged Care*. Australian (Research Centre in Sex, Health & Society, 2015) <https://www.opalinstitute.org/uploads/1/5/3/9/15399992/intersexguide.pdf>.

<sup>22</sup> For example, see Council of Europe Parliamentary Assembly, "'Older intersex people need our support', urges General Rapporteur on Intersex Awareness Day 2022" (Oct. 25, 2022), <https://pace.coe.int/en/news/8874/-older-intersex-people-need-our-support-urges-general-rapporteur-on-intersex-awareness-day-2022>. Notably, The Council of Europe's General Rapporteur on LGBTI rights recently urged expanded research on older adults with intersex variations, stating: "For older intersex people, the long-term impact of intersex genital mutilation, secrecy, shame and lack of access to medical records may be devastating, resulting in lasting distrust of medical professionals, fear of institutionalisation and lack of access to necessary health care. Lack of family support as well as lower income levels due to discrimination in education and employment may moreover lead to isolation and poverty in later life."

## Recommendations for implementation of the proposed SOGI measures

As ACL adopts the proposed SOGI measures on the SOOA, we encourage the agency to assess write-in responses to the free-text option for questions about sexual orientation and current gender, which may inform research and testing of terminology on future iterations of the SOOA or other ACL surveys. Additionally, we urge ACL to invest in research and testing to examine how the proposed SOGI measures perform for beneficiaries with cognitive or developmental disabilities who are served by SHIP-SMP programs. Our organizations have heard from ACL grantees that welcome efforts to improve data collection to learn more about the needs of LGBTQ+ beneficiaries, but also expressed a need to ensure that the proposed questions are comprehended and accurately responded to by these beneficiaries.

More broadly, as ACL adds SOGI measures to the SOOA, we urge the agency to:

- Provide training and education for SHIP-SMP grantees to ensure they are well-versed on topics that may be of particular interest to LGBTQI+ beneficiaries and can explain benefits and options related to that care in a culturally competent manner.
- Share findings based on the collection of SOGI data on SOOA to the public and LGBTQI+ stakeholders to raise awareness about the needs of LGBTQI+ beneficiaries and support data-driven policymaking and advocacy.
- Ensure that beneficiaries' SOGI data are analyzed, maintained, and shared with rigorous privacy and confidentiality standards in place and upheld consistent with existing legal requirements and stewardship practices. These protections should be communicated in plain language with respondents.

## Conclusion

We strongly support ACL's proposal to add SOGI measures to the SGOEE for SHIP-SMP programs and its cross-agency policy to collect sexual orientation and gender identity demographic data in all information collection requests where other demographic information is collected for purposes other than program eligibility.<sup>23</sup> We also encourage ACL to devote resources to testing a measure of variations in sex characteristics that can identify intersex individuals in this and other ACL surveys, and to coordinate with other agencies on advancing this area of data collection. Finally, we urge ACL to support successful implementation of new SOGI measures by offering appropriate grantee training and support, and ensuring data analysis and reporting that are both robust and adequately protect privacy.

Thank you for your consideration. Please do not hesitate to contact Caroline Medina, [CMedina@Whitman-Walker.org](mailto:CMedina@Whitman-Walker.org), if you need any additional information.

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<sup>23</sup> Office of Management and Budget, "ACL SOGI Data Collection Policy," available at <https://omb.report/icr/202306-0985-001/doc/133679600> (last accessed July 2023)

Sincerely,

Whitman-Walker Institute  
SAGE Center of Excellence  
Movement Advancement Project