

November 28, 2023

Submitted via Regulations.gov

Centers for Medicare & Medicaid Services
Office of Strategic Operations and Regulatory Affairs
Division of Regulations Development
7500 Security Boulevard
Baltimore, Maryland 21244-1850

RE: CMS-10718, Model Medicare Advantage and Prescription Drug Plan Individual Enrollment Form

The 29 undersigned organizations appreciate the opportunity to provide these comments on the Department of Health and Human Services (HHS) Model Medicare Advantage and Prescription Drug Plan Individual Enrollment Form, CMS-10718.¹

We strongly support the addition of fields to collect information on enrollees' sexual orientation and gender identity (SOGI). Obtaining this information on the enrollment form will greatly improve CMS's ability to track patterns in enrollment over time; identify, monitor, and develop effective and efficient strategies and incentives to reduce and eliminate health and health care inequities; ensure clinically appropriate and equitable care is provided consistently; and meet its obligations under Executive Order 13985.² We also recommend CMS collect preferred language and disability data on these forms to enhance data equity for intersectional populations.

Collecting SOGI Data on the Enrollment Form Advances Equity

The addition of SOGI fields to the Enrollment Form is a critical step on the path to health equity for LGBTQI+ people. As CMS has acknowledged in its *Framework for Health Equity 2022-32*, and *Equity Plan for Improving Quality in Medicare*, the LGBTQI+ community faces significant health disparities, and comprehensive data collection is "required to plan for quality improvements, and to address changes...over time."³ The

¹ Agency Information Collection Activities: Proposed Collection; Comment Request; Exhibit 1: Model Individual Enrollment Request Form to Enroll in a Medicare Advantage Plan (Part C) or Prescription Drug Plan (Part D), 88 Fed. Reg. 67298 (Sept. 29, 2023).

² Exec. Order No. 13985, 86 Fed. Reg. 7009 (Jan. 25, 2021), <https://www.federalregister.gov/documents/2021/01/25/2021-01753/advancing-racial-equity-and-support-for-underserved-communities-through-the-federal-government>.

³ Ctrs. Medicare & Medicaid Servs., Ofc. Minority Health, *The CMS Equity Plan for Improving Quality in Medicare* 8 (2015), <https://www.cms.gov/About-CMS/Agency->

proposed addition of SOGI fields to the Enrollment Form builds on the work CMS and HHS have done in response to Executive Order 13985, which calls for federal agencies to “expand and refine the data available to the Federal Government to measure equity and capture the diversity of the American people,” as well as HHS’s 2023 SOGI Data Action Plan, which commits to collect SOGI data wherever demographic information is collected for surveillance, monitoring, research, and other purposes not related to eligibility.⁴

Despite consistent evidence of disparities and inequities in health care access and outcomes faced by LGBTQI+ people, CMS has not previously collected program administrative data that would identify and track the distinct experiences of lesbian, gay, bisexual, transgender, queer, and intersex populations.⁵ The adoption of SOGI fields on the Enrollment Form will vastly expand our understanding of LGBTQI+ health and health care experiences in Medicare, as more than half of the Medicare-enrolled population is enrolled in a Part C plan (about 31 million people), and about three-quarters are enrolled in a Part D plan (about 48 million people).⁶ In conjunction with the initiation of SOGI data collection on the single, streamlined Federally-Facilitated Marketplace application, this new data has the potential to transform our broader understanding of LGBTQI+ health care access, quality, and outcomes and to drive targeted actions to address long-standing health disparities.⁷

[Information/OMH/OMH_Dwnld-CMS_EquityPlanforMedicare_090615.pdf](#), Ctrs. for Medicare & Medicaid Servs., *CMS Framework for Health Equity 2022-2032*, <https://www.cms.gov/files/document/cms-framework-health-equity.pdf>.

⁴ Exec. Order No. 13985, (Jan. 20, 2021); Dep’t Health & Hum. Servs., *HHS SOGI Data Action Plan* (2023).

⁵ For detailed discussion of health disparities, see Nat’l Acad. Scis., Eng’g, & Med., *Understanding the Well-Being of LGBTQ Populations* 287-342 (2020), <https://nap.nationalacademies.org/read/25877/>.

⁶ Nancy Ochieng et al., *Medicare Advantage in 2023: Enrollment Updates and Key Trends* KFF, (Aug. 9, 2023), <https://www.kff.org/medicare/issue-brief/medicare-advantage-in-2023-enrollment-update-and-key-trends/#:~:text=Key%20highlights%20include%3A,Advantage%20varies%20widely%20across%20counties>; Ctrs. for Medicare & Medicaid Servs., *CMS Program Statistics – Medicare Part D Enrollment* (2021), <https://data.cms.gov/summary-statistics-on-beneficiary-enrollment/medicare-and-medicare-reports/cms-program-statistics-medicare-part-d-enrollment>.

⁷ See Naomi Goldberg, Movement Advancement Project & Nat’l Health L. Program, *Administrative Data: Providing Information to Advance Autonomy and Drive Equality* (Feb. 2023), <https://healthlaw.org/wp-content/uploads/2023/02/Drive-Equality-MAP-NHeLP-Jan2023-2.pdf>.

As a next step, we recommend CMS should also add SOGI demographic fields to the Medicare Part B Application for Enrollment Form. By adding SOGI fields to the Part B Enrollment Form, CMS could reach over 90% of the Medicare-enrolled population.⁸

In addition, as recommended by the HHS SOGI Data Action Plan, CMS should invest in testing methods of identifying intersex populations and adding intersex demographic fields, or fields that address variations in sex characteristics, to this Enrollment Form and wherever CMS collects demographic information. Particularly because the intersex population is a smaller subpopulation of individuals, the greater the reach of the data collection, the better the resulting data. With a broad administrative data collection such as the Medicare program, CMS has the ability to not only illuminate intersex experiences within the program, but also to expand the collective knowledge on LGBTQI+ health and health care generally.

Finally, we urge CMS to work with other HHS subagencies to adopt a standardized measure for collecting data on sexual orientation, gender identity, and variations in sex characteristics (SOGISC) in all HHS programs. Although we overwhelmingly support the immediate adoption of a SOGI measure on the Enrollment Form, the question format and response options selected do not align with those recommended by the expert report commissioned by the National Institutes of Health and adopted by other subagencies such as the Administration for Community Living.⁹ Particularly because these programs often serve the same populations (e.g., older adults, people with low- or no incomes, and people with disabilities), adopting a standardized measure is critical to maximize the usefulness of data obtained.

Adding Fields for Disability and Language Demographic Information Further Advances Equity for LGBTQI+ People

While our groups have long advocated for CMS to adopt SOGISC demographic variables, it should be emphasized that these variables are neither mutually exclusive nor unrelated to other demographic characteristics, including race, ethnicity, age,

⁸ See Asst. Sec. of Planning & Evaluation (ASPE), Ofc. of Health Policy, *Issue Brief: Medicare Beneficiary Enrollment Trends and Demographic Characteristics* (Mar. 2, 2022), <https://aspe.hhs.gov/sites/default/files/documents/f81aafbba0b331c71c6e8bc66512e25d/medicare-beneficiary-enrollment-ib.pdf>.

⁹ See Nat'l Acads. Scis., Eng'g, Med., *Measuring Sex, Gender Identity, and Sexual Orientation* (2022), <https://nap.nationalacademies.org/catalog/26424/measuring-sex-gender-identity-and-sexual-orientation>; Admin. Community Living, *Agency Information Collection Activities; Submission for OMB Review; Public Comment Request; SHIP-SMP Survey of One-on-One Assistance*, 88 Fed. Reg. 43357 (2023), <https://www.federalregister.gov/documents/2023/07/07/2023-14336/agency-information-collection-activities-submission-for-omb-review-public-comment-request-ship-smp>.

language, and disability. Each of these demographic characteristics interact to shape an individual's experience accessing health care and achieving good health. At the community and population level, these variables, both individually and in combination, illustrate where programs and health systems perpetuate barriers and discrimination.

In particular, we want to highlight the great unmet need for demographic data on disability and preferred language. Both disability and LEP populations experience well-documented, long-standing inequities that, were these populations identified as such at enrollment, could be targeted and addressed. Further, demographic information on these populations collected at enrollment could be more broadly used to plan for language accessibility and other accommodations. For example, collecting language data could help agencies, health care insurers and providers know which patients will need interpreting in advance of a scheduled visit.

This lack of disability and language demographic data also has an impact on the understanding of LGBTQI+ experiences and health equity.¹⁰ Prevalence estimates from private and state-based survey data indicate that LGBTQI+ people are more likely to have a disability than non-LGBTQI+ people.¹¹ Private survey data illustrates the compounding effect of discrimination and barriers on LGBTQI+ people with disabilities and LGBTQI+ people who are also LEP.¹² Yet, the Medicare program has not improved its collection of disability and language information as demographic measures in tandem with its collection of SOGI and race and ethnicity.¹³

¹⁰ See, e.g., Lacey Hartman & Karen Turner, State Health Access and Data Assistance Ctr. (SHADAC), Medicaid and CHIP Payment and Access Com'n. (MACPAC), *Federal Survey Sample Size Analysis: Disability, Language, and Sexual Orientation and Gender Identity* at 7-8 (Sept. 14, 2023), <https://www.macpac.gov/wp-content/uploads/2023/10/Federal-Survey-Sample-Size-Analysis-Disability-Language-and-Sexual-Orientation-and-Gender-Identity.pdf>, highlighting the lack of data that would allow for comparability of multiple demographic characteristics in Medicaid and national survey data.

¹¹ Movement Advancement Project, Ctr. for Am. Progress, Nat'l Ctr. for Lesbian Rts., & Nat'l LGBTQ Task Force, *LGBT People with Disabilities*, <https://www.lgbtmap.org/file/LGBT-People-With-Disabilities.pdf> (last visited Oct. 20, 2023).

¹² See Caroline Medina & Lindsay Mahowald, Ctr. Am. Progress, *Discrimination and Barriers to Well-Being: The State of the LGBTQI+ Community in 2022* (Jan. 12, 2023), <https://www.americanprogress.org/article/discrimination-and-barriers-to-well-being-the-state-of-the-lgbtqi-community-in-2022/>; Nat'l Ctr. Trans Equality, *The Report of the 2015 U.S. Trans Survey* (Dec. 2015), <https://transequality.org/sites/default/files/docs/usts/USTS-Full-Report-Dec17.pdf>; M.V. Lee Badgett, Soon Kyu Choi, & Bianca D.M. Wilson, Williams Inst., *LGBT Poverty in the United States: A study of differences between sexual orientation and gender identity groups* 17-23 (Oct. 2019), <https://williamsinstitute.law.ucla.edu/wp-content/uploads/National-LGBT-Poverty-Oct-2019.pdf>.

¹³ Dep't of Health & Hum. Servs., Ass't Sec. for Planning & Evaluation, *HHS Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and*

We urge CMS not to delay in adopting detailed disability and preferred language along with other demographic measures collected by its programs.

Conclusion

Thank you for considering our comments on this important health equity issue. We have included numerous citations to supporting research, including direct links to the research. We direct CMS to each of the materials cited and made available through active links, and we request that the full text of each of the studies and articles cited, along with the full text of our comment, be considered part of the formal administrative record for purposes of the Administrative Procedures Act. If CMS is not planning to consider these materials part of the record as we have requested here, we ask that you notify us and provide us an opportunity to submit copies of the studies and articles into the record.

Please contact Charly Gilfoil, Staff Attorney at the National Health Law Program, at gilfoil@healthlaw.org for follow up on this comment letter or additional information.

Sincerely,

Advocates for Youth
American College of Obstetricians and Gynecologists
American Federation of State, County & Municipal Employees
Association of Asian Pacific Community Health Organizations (AAPCHO)
Blue Future
Caring Across Generations
Community Catalyst
COVID Survivors for Change
Disability Rights Education and Defense Fund (DREDF)
National Health Law Program
Human Rights Campaign
interACT: Advocates for Intersex Youth
Ipas
Japanese American Citizens League (JACL)
Justice in Aging
The Leadership Conference for Civil and Human Rights

Disability Status (Oct. 30, 2011), <https://aspe.hhs.gov/reports/hhs-implementation-guidance-data-collection-standards-race-ethnicity-sex-primary-language-disability-0>.

**League of Women Voters of the United States
Movement Advancement Project
National Association of Social Workers
National Center for Parent Leadership, Advocacy, and Community
Empowerment (National PLACE)
National Council of Asian Pacific Americans (NCAPA)
National Organization for Women
National Partnership for Women & Families
SAGE (Advocacy and Services for LGBTQ+ Elders)
South Asian Public Health Association
The Trevor Project
Transhealth
Whitman-Walker Institute**