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March 14, 2022

The Honorable Chiquita Brooks-LaSure
Administrator
Centers for Medicare and Medicaid Services
Department of Health and Human Services
P.O. Box 8016
Baltimore, MD 21244-8016

**RE: Comments on Model Medicare Advantage and
Medicare Prescription Drug Plan Enrollment Form,
CMS-10718, OMB 0938-1378**

Dear Administrator Brooks-LaSure,

The National Health Law Program (NHeLP), founded in 1969, protects and advances health rights of low-income and underserved individuals and families by advocating, educating, and litigating at the federal and state levels. We thank you for the opportunity to comment on the proposed Medicare Part C & D Model Enrollment Form and to provide additional suggestions that further the Biden-Harris Administration's stated goal of advancing health equity.

Collection, analysis and access to comprehensive demographic data across federally supported health insurance programs is essential for health care professionals, policymakers, and other stakeholders to be able to identify, monitor, and develop targeted strategies to mitigate health disparities. Health status and health care utilization disparities persist, and in some cases have widened across many demographics including race/ethnicity, socioeconomic status, sex characteristics, gender identity, sexual orientation, disability status, and English proficiency. However, efforts to identify disparities and implement solutions to reduce them have been inhibited by a lack of specificity, uniformity, and quality in data collection and reporting procedures. Without specific, standardized requirements for demographic data collection, cross-plan or cross-program comparisons are difficult if not impossible.

I. General Recommendations

We strongly support CMS' plan to add mandatory race and ethnicity questions to the model MA and PDP Enrollment Form and to evaluate enrollee responses to these questions via focus groups. As Administrator Brooks-LaSure has acknowledged, achieving health equity must include data collection, reporting, and analysis to identify disparities and track improvements.¹ While the existence of health disparities has been well documented, the complex factors that contribute to and mitigate against them are still not fully understood. In part, this is due to a lack of high quality, large scale, and easily available data. For example, data on smaller populations is often not extensive enough to lend itself to meaningful analysis. Similarly, data is often not available for intersecting sub-populations that might experience multiple barriers to access.

Despite years of consensus on the importance of demographic data collection among CMS, HHS, and expert health and medical associations such as the Joint Commission,² Institutes of Medicine,³ AMA⁴, NAIC,⁵ AHIP,⁶ and the public,⁷ uniform and comprehensive demographic data collection in federally-funded health programs is exceedingly rare. Currently, the race and ethnicity of individuals who enroll in Medicare are not self-reported; this data comes from the

¹ Seshamani, Meena, Elizabeth Fowler, and Chiquita Brooks-LaSure, Building on the CMS Strategic Vision: Working Together For a Stronger Medicare, Health Affairs (Jan. 11, 2022), <https://www.healthaffairs.org/doi/10.1377/forefront.20220110.198444>.

² See R3 Report: Patient-centered communication standards for hospitals, The Joint Commission (Feb. 9, 2011), <https://www.jointcommission.org/-/media/tjc/documents/standards/r3-reports/r3-report-issue-1-20111.pdf>.

³ See Ulmer, Cheryl, Bernadette McFadden, David R. Nerenz, Eds., Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement, Institute of Medicine (2009), <https://www.ahrq.gov/sites/default/files/publications/files/iomracereport.pdf>.

⁴ See Promoting Inclusive Gender, Sex, and Sexual Orientation Options on Medical Documentation, AMA: Policy Finder (2019) <https://policysearch.ama-assn.org/policyfinder/detail/sexual%20orientation%20and%20gender%20identity?uri=%2FAMADoc%2FHOD-315.967.xml>; Accurate Collection of Preferred Language and Disaggregated Race and Ethnicity to Characterize Health Disparities, AMA: Policy Finder (2019) <https://policysearch.ama-assn.org/policyfinder/detail/race%20ethnicity?uri=%2FAMADoc%2FHOD.xml-H-315.963.xml>.

⁵ See Draft Principles for Data Collection, Nat'l Assoc. of Insurance Commissioners (Dec. 3, 2021), https://content.naic.org/cmte_ex_race_and_insurance.htm.

⁶ See AHIP Comments on OMB Racial Equity RFI (Jul. 2, 2021), <https://www.ahip.org/documents/comment-letters/AHIP-Response-to-OMB-Equity-RFI-July-2021.pdf>.

⁷ See, e.g., Baker D.W., K.A. Cameron, J. Feinglass, P. Georgas, S. Foster, D. Pierce, et al., Patients' attitudes toward health care providers collecting information about their race and ethnicity, J. Gen. Internal Med. (2005), <https://pubmed.ncbi.nlm.nih.gov/16191134/>



Social Security Administration's (SSA) records.⁸ However, after 1989, SSA ceased regular collection of race and ethnicity data, leaving many Medicare recipients' demographic information completely unrecorded.⁹

We write in support of the changes proposed to the model MA and PDP enrollment form and also in hopes that CMS will take this opportunity to go further. First, the race and ethnicity questions proposed can only be effective to track disparities and identify appropriate interventions if they recognize important U.S. subpopulations at a sufficient level of granularity. CMS should make several key changes to maximize the effect of their efforts before launching the new model form and conducting focus groups. Second, CMS should also add questions that capture sex, sex characteristics, sexual orientation, gender identity, and disability as recommended by an abundance of research by subject-matter experts. The recently released NASEM report provides the most up-to-date, evidence-based recommendations on the best way to collect information on individual enrollees' sex, sexual orientation, gender identity, and sex characteristics.¹⁰ Third, CMS should revise the question about primary language to enable demographic identification of limited English-proficient (LEP) individuals. While the current forms seek information about an enrollee's language, the collection is limited to languages in which plans have to provide translated information. Instead, CMS should collect primary language of all applicants as this information can be used for planning purposes by plans and providers and not merely identify which individuals are eligible to receive a translated document. Finally, CMS should add validated disability questions that appropriately capture mental and functional status. In addition to the six-question series on disability and functional status that is already part of HHS' data collection practices, CMS should adopt additional questions on communication, learning, and psychological disabilities.

We would like to offer the following recommendations that apply to collection of all types of demographic data.

⁸ See James, Cara, Barbara Lyons, Philip A. Saynisch, and Sarah Hudson Scholle, *Modernizing Race and Ethnicity in Our Federal Health Programs*, The Commonwealth Fund (Oct. 26, 2021), <https://www.commonwealthfund.org/blog/2021/modernizing-race-and-ethnicity-data-our-federal-health-programs>.

⁹ Martin, Patricia P., *Why Researchers Now Rely on Surveys for Race Data on OASDI and SSI Programs: A Comparison of Four Major Surveys*, ssa.gov (Jan. 2016), <https://www.ssa.gov/policy/docs/rsnotes/rsn2016-01.html#mn1>.

¹⁰ Bates, Nancy, Marshall Chin, and Tara Becker, Eds., *Measuring Sex, Gender Identity, and Sexual Orientation*, Nat'l Academies of Sciences, Engineering, and Medicine (2022), <https://www.nap.edu/read/26424/chapter/1> [hereafter, "NASEM Report"].



a. Collect comprehensive demographic data beyond race and ethnicity

As we detail in parts II, III, and IV below, we urge CMS to collect demographic information at Medicare enrollment in sufficient detail to allow for meaningful analysis of enrollees' access to care. CMS must not only collect information about enrollees' race and ethnicity but also their preferred language, gender identity, sexual orientation, sex characteristics, and disability status. We need comprehensive demographic data on a broader set of identifying characteristics so that we can begin to address disparities in populations that we know have been historically underserved. Further, demographic data collection must be intersectional in its approach to account for the ways that sub-populations experience multiple disparities. In our increasingly multicultural society, it is vital that CMS activities support analyses based on multiple demographic variables.

b. Engage regular community input and feedback

Distinct communities are experts on their own data and should be centered in any approach to engage in widespread data collection. Input from members of diverse groups generates higher participation and response rates, ensures that terminology used is culturally appropriate, and improves transparency and accountability.¹¹ We support CMS' use of focus groups for testing and community feedback to revise the race/ethnicity questions used on the model enrollment form. We encourage CMS to look for ways to incorporate regular stakeholder feedback, such as community advisory boards, in its data collection efforts. Regular review of responses and community input can ensure that response options are valid and representative of the general population.¹²

c. Ensure information is self-reported

We support the inclusion of race/ethnicity questions on the model enrollment form, which sets a mandatory floor for plans to include at enrollment. We urge CMS to make clear to Medicare Part C and D enrollees that their individual responses to these questions are strictly voluntary and should be self-reported to ensure accuracy. CMS recognizes the need to conduct education and training of plan-level staff to be able to engage enrollees on the importance of providing this information. However, this education and training should also emphasize that the

¹¹ Wang, Karen, Theresa Cullen, Marcella Nunez-Smith, Centering Equity in the Design and Use of Health Information Systems: Partnering with Communities on Race, Ethnicity, and Language Data, *Health Affairs* (May 19, 2021), <https://www.healthaffairs.org/doi/10.1377/forefront.20210514.126700/full/>.

¹² See *Id.*



individual enrollee shall not be penalized for failing to provide demographic information at enrollment.

d. Provide support and training for staff charged with collecting information

We appreciate that CMS, in its supporting statement, acknowledges that it will be necessary to provide education and technical support for plans to be able to implement this new data collection accurately. Many on the health care provider side worry that asking these questions causes discomfort or offense, contributes to discrimination, or jeopardizes patient privacy.¹³ Yet, research shows that a majority of patients support the collection of race/ethnicity¹⁴ and sexual orientation, gender identity, and sex characteristics (SOGISC) data¹⁵ to address disparities. We recommend that CMS provide plan staff with resources to explain why demographic data is being collected, how enrollees' privacy will be protected, how and with whom the data will be shared, and how the data will be used.¹⁶

We also suggest that CMS consider asking questions in the focus groups to ascertain the best rationales to utilize when asking individuals for demographic data. In the early 2000's, AHA's Health Research and Educational Trust tested four different explanations for collecting race, ethnicity and language data in hospital settings at admission and developed a toolkit about collecting data.¹⁷ We believe similar research is needed to identify the best ways to request this information on applications, particularly when individuals apply in person or over-the-

¹³ Hasnain-Wynia, Romana, Debra Pierce, Mary A. Pittman, Who, When, and How: The Current State of Race, Ethnicity, and Primary Language Data Collection in Hospitals, Health Research and Educational Trust, The Commonwealth Fund (May 2004), https://www.commonwealthfund.org/sites/default/files/documents/media_files_publications_fund_report_2004_may_who_when_and_how_the_current_state_of_race_ethnicity_and_primary_language_data_collection_in_ho_hasnain_wynia_whowhenhow_726_pdf.pdf.

¹⁴ Baker D.W., K.A. Cameron, J. Feinglass, P. Georgas, S. Foster, D. Pierce, et al., Patients' attitudes toward health care providers collecting information about their race and ethnicity, J. Gen. Internal Med. (2005), <https://pubmed.ncbi.nlm.nih.gov/16191134/>.

¹⁵ Cahill, Sean, Robbie Singal, Chris Grasso, Dana King, Kenneth Mayer, Kellan Baker, Harvey Makadon, 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, PLoS One (2014), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4157837/pdf/pone.0107104.pdf>.

¹⁶ See Grasso, Chris, Michal McDowell, Hilary Goldhammer, Alex S. Keuroghlian, Planning and implementing sexual orientation and gender identity data collection in electronic health records, J. Am. Med. Inform. Assoc. (2018), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6657380/pdf/ocy137.pdf>.

¹⁷ Health Research and Educational Trust Disparities Toolkit, AHA Institute for Diversity and Health Equity (2007), <https://ifdhe.aha.org/hretdisparities/toolkit>.



phone. This information would also be relevant for training the staff – Call Center staff, plan staff, or assisters – who ask applicants for this information.

e. Use data for accountability, accessibility, and cultural competency

Demographic data collection not only helps plans, providers, and policymakers measure quality of care at a population level, it can also help improve quality of care at an individual level. Broad collection of demographic data is integral to understanding whether a particular program is upholding civil rights requirements and improving the outcomes of historically underserved groups. Without this data, average improvement across all groups could mask a lack of improvement or even deterioration in outcomes for a specific population. Disaggregated data allows plans to target interventions that address specific inequities. Further, plans can use this data to foster accessibility and cultural competency throughout the health care system. Capturing data about an individual enrollee's disabilities and functional status at the enrollment stage allows that individual's providers to plan for accommodations that improve quality of care. Similarly, capturing primary language at enrollment can be used by the plan to identify how best to provide language services in its Call Center and operations and can be shared with providers to appropriately develop language services for their patients. Providers can also use plan-level enrollment data to understand which racial and ethnic populations use particular health systems and take steps to improve their cultural competency.¹⁸ Accountability means that data will be used not just to track disparities but to use that data to provide better quality of care to enrollees.

f. Emphasize privacy protections

We recommend that CMS take steps to ensure that demographic data collected is maintained safely and securely by the appropriate entities. Strict standards must be adopted to ensure that data cannot be used for negative actions such as immigration or law enforcement, redlining or targeting of specific groups. Policies must enable individuals to feel comfortable disclosing personal information. We encourage CMS to ensure that the privacy protections applied to demographic data comply with the privacy and security standards set forth in ACA Section 3101, which built upon the privacy protections required by HIPAA. Individuals should be made aware of their privacy protections and rights and have a clear understanding of why demographic data is being collected and who will have access to which forms of information.

¹⁸ See, e.g., Yi, Stella S., Simona C. Kwon, Lan N. Doan, Iyanrick John, Nadia S. Islam, and Chau Trinh-Shevrin, The Mutually Reinforcing Cycle of Poor Data Quality and Racialized Stereotypes That Shapes Asian American Health, *Health Affairs* (Feb. 2022), <https://www.healthaffairs.org/doi/10.1377/hlthaff.2021.01417>.



II. Collecting Race and Ethnicity Data

We strongly support CMS' decision to collect race and ethnicity demographic information on the MA and PDP model enrollment form. As CMS refocuses on health equity, it is necessary for CMS to acknowledge, along with the broad consensus of health and medical experts, that racial inequities in the health care system exist and must be measured in order to be addressed. Further, research shows high individual support for actions to use data collection to address disparities and a low nonresponse rate to demographic survey questions.¹⁹ About 80% of one study's participants somewhat or strongly agreed that hospitals and clinics should collect information on race and ethnicity, and virtually all agreed that the demographic information should be used to better train staff to treat patients of different backgrounds.²⁰

Therefore, we support the use of required, uniform language in both questions and response options on the model enrollment form. A requirement for plans and entities to collect uniform data across the Medicare part C- and D-enrolled population will enable comparability and validity of data and improve accuracy of findings from data analysis.²¹ CMS should standardize both the question stems and response options in order to maximize comparability

¹⁹ See Baker D.W., K.A. Cameron, J. Feinglass, P. Georgas, S. Foster, D. Pierce, et al., Patients' attitudes toward health care providers collecting information about their race and ethnicity, *J. Gen. Internal Med.* (2005), <https://pubmed.ncbi.nlm.nih.gov/16191134/>. And see Bentley, Michael and Sarah Konya, 2020 Census Operational Quality Metrics: Item Nonresponse Rates, U.S. Census Bureau (Aug. 21, 2021), <https://www.census.gov/newsroom/blogs/random-samplings/2021/08/2020-census-operational-quality-metrics-item-nonresponse-rates.html>, which found nonresponse rate for 2020 Census race/ethnicity question to be less than the 5.95% threshold that the Census Bureau considers to be "low."

²⁰ Baker D.W., K.A. Cameron, J. Feinglass, P. Georgas, S. Foster, D. Pierce, et al., Patients' attitudes toward health care providers collecting information about their race and ethnicity, *J. Gen. Internal Med.* (2005), <https://pubmed.ncbi.nlm.nih.gov/16191134/>.

²¹ See Hasnain-Wynia, Romana, Debra Pierce, Mary A. Pittman, Who, When, and How: The Current State of Race, Ethnicity, and Primary Language Data Collection in Hospitals, Health Research and Educational Trust, The Commonwealth Fund (May 2004), https://www.commonwealthfund.org/sites/default/files/documents/media_files_publications_fund_report_2004_may_who_when_and_how_the_current_state_of_race_ethnicity_and_primary_language_data_collection_in_ho_hasnain_wynia_whowhenhow_726.pdf; Ulmer, Cheryl, Bernadette McFadden, David R. Nerenz, Eds., *Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement*, Institute of Medicine (2009), <https://www.ahrq.gov/sites/default/files/publications/files/iomracereport.pdf>.



and to obtain a sample size for racial and ethnic subpopulations that enables meaningful analysis of disparities among lesser-studied groups.²²

Before adopting questions and response options for the final model enrollment form, we urge CMS to consider several recommendations on how to improve race/ethnicity data collection. First, CMS should consider combining the race and ethnicity questions into one question. Research from the Census Bureau has shown that a one-question format aligns with how individuals see themselves, improves response rate, and increases the likelihood that individuals self-report accurately.²³ To avoid confusion, we suggest phrasing the question as, “what is your race/ethnicity?” Second, CMS should revise the response options to add more subcategories for Latino, Asian American, Native Hawaiian, Pacific Islander, and Middle Eastern and North African populations. CMS should consult with tribal nations on the best ways to collect and report tribal data for indigenous populations. To the extent possible, remove the use of an “other” category and add a space where the enrollee can fill in the blank. CMS should make it clear both on the form and in the use of the form that enrollees may check or write in as many answers as is meaningful to them. Third, CMS should require plans to use the response options that it provides on the model enrollment form in order to ensure uniformity of data collected. While it is clear from the supporting statement that plans will be required to ask the provided questions, the data collection will not be as valid or useful if plans use a variety of response options. Finally, CMS should establish a revision process for the standardized language used on the form and periodically review both the questions and response options. Periodic review will enable updates that reflect the way individuals see themselves, account for changing populations, and allow for research and testing of new demographic response options.

²² See Rodriguez-Lainz, McDonald, Fonseca-Ford, Penman-Aguilar, Waterman, Truman, Cetron, and Richards, Collection of Data on Race, Ethnicity, Language, and Nativity by US Public Health Surveillance and Monitoring Systems: Gaps and Opportunities, 133 Pub. Health Rep 1 (2018), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5805104/pdf/10.1177_0033354917745503.pdf and Bernard, Sydney, Carrie Au-Yeung, Collection and Availability of Data on Race, Ethnicity, and Immigrant Groups in Federal Surveys that Measure Health Insurance Coverage and Access to Care, State Health Access Data Assistance Center (Sept. 2021), <https://www.shadac.org/sites/default/files/publications/REI%20brief%20Final.pdf>.

²³ Marks, Rachel, Nicholas Jones, Collecting and Tabulating Ethnicity and Race Responses in the 2020 Census, U.S. Census Bureau (Feb. 2020), <https://www2.census.gov/about/training-workshops/2020/2020-02-19-pop-presentation.pdf>; Cohn, D’Vera, Anna Brown, Mark Hugo Lopez, Only about half of Americans say Census questions reflect their identity well, Pew Research Center (May 14, 2021), <https://www.pewresearch.org/social-trends/2021/05/14/only-about-half-of-americans-say-census-questions-reflect-their-identity-very-well/>.



III. Collecting Primary Language Data

LEP individuals face intersecting barriers in access and face demonstrated inequities in health outcomes. According to a 2017 HHS report, approximately 8% of Medicare beneficiaries are limited English Proficient (LEP).²⁴ As HHS notes:

Understanding and addressing communication and language assistance needs are essential to successful delivery of high quality health care because communication and language barriers are associated with decreased quality of care and poor clinical outcomes.²⁵

In order to determine informed remedies, we strongly recommend that CMS either modify its primary language question to ensure that it can collect data on all individuals who are LEP or add a new question to collect language data from all applicants. The proposed enrollment form includes one question on language that the plan should use to send information to the enrollee. However, it is unclear whether the question captures information on the enrollee's primary language as a demographic identifier. As noted in our above recommendations, identifying LEP enrollees enables CMS to track disparities and target solutions that address inequities in access. Past research has shown that Medicare enrollees who are LEP are less likely to have preventative screenings, less likely to have a usual source of health care, and more likely to have difficulty communicating with providers than non-LEP Medicare enrollees.²⁶ Without collecting information on enrollees' primary language, CMS can neither address these issues nor determine whether LEP enrollees' access to and quality of care has improved.

We recommend comprehensive collection of applicant's preferred language in part so that entities can appropriately develop communication plans and have services in place to correct inequities and facilitate better quality of care for LEP enrollees. Having comprehensive language data will assist plans understand the scope of the populations they serve and the prevalence of specific language groups in their enrollees. Depending on an entity's size and scope, advance planning need not be exhaustive but is important to ensure that effective

²⁴ Understanding Communication and Language Needs of Medicare Beneficiaries, Ctrs. for Medicare and Medicaid Svcs., at 8 (Apr. 2017), <https://www.cms.gov/About-CMS/Agency-Information/OMH/Downloads/Issue-Briefs-Understanding-Communication-and-Language-Needs-of-Medicare-Beneficiaries.pdf>.

²⁵ *Id.* at 18.

²⁶ Ponce, Ninez A., Leighton Ku, William E. Cunningham, E. Richard Brown, Language Barriers to Health Care Access Among Medicare Beneficiaries, *Inquiry* (2006), https://journals.sagepub.com/doi/pdf/10.5034/inquiryjrnl_43.1.66.



communication will occur and that entities comply with their obligations under Title VI of the Civil Rights Act of 1964 and Section 1557 of the Affordable Care Act.

Our experience is that entities are in a better position to meet their obligations to provide language assistance services in a timely manner when those entities identify, in advance, the types and levels of services available in each of the contexts in which the covered entity encounters individuals who are LEP.

IV. Collecting Sexual Orientation, Gender Identity, and Sex Characteristics (SOGISC) Data

Since at least 2001, HHS has recognized the staggering health inequities that LGBTQI individuals face.²⁷ Yet, in 2022 few HHS programs routinely collect data on gender identity, sexual orientation, sex, or sex characteristics. Enabling enrollees to self-report SOGISC information in order to understand and correct these disparities is a broadly supported, necessary step in the path to equality.²⁸ Without access to the broad base of data that could be collected as part of federal programs, stakeholder groups and nonprofits have taken to funding their own research that demonstrates the great number of disparities that LGBTQI individuals face in accessing quality health care.²⁹ However, these data will never carry the same weight as a nationally representative sample, nor do they serve the same purpose of addressing specific disparities that occur within the system. As a result, the promise of health equity for LGBTQI enrollees remains unfulfilled.

We strongly recommend that CMS take this opportunity to initiate collection of SOGISC demographic data via the model enrollment form. The resources, research, and information needed to support population-wide SOGISC data collection already exist in the work done by

²⁷ See Healthy People 2010: Companion Document for Lesbian, Gay, Bisexual, and Transgender (LGBT) Health, Gay and Lesbian Med. Assoc. (2001), https://www.gлма.org/data/n_0001/resources/live/HealthyCompanionDoc3.pdf.

²⁸ See Cahill, Sean, Robbie Singal, Chris Grasso, Dana King, Kenneth Mayer, Kellan Baker, Harvey Makadon, 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, PLoS One (2014), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4157837/pdf/pone.0107104.pdf>.

²⁹ See, e.g., 2015 U.S. Transgender Survey, Nat'l Ctr. For Transgender Equality (2016), <https://www.ustranssurvey.org/reports>; When Health Care Isn't Caring, Lambda Legal (2010), https://www.lambdalegal.org/sites/default/files/publications/downloads/whcic-report_when-health-care-isnt-caring.pdf.



HHS by its 2016 LGBT Policy Coordinating Committee³⁰ and CMS in its 2016 Medicare Current Beneficiary Survey study,³¹ as well as by private groups seeking to understand LGBTQI health.³²

The recently released NASEM report provides the most up-to-date expert recommendations on how to ask SOGI-related questions on self-reported forms as well as recommended practices for agencies and institutions to conduct reliable and culturally competent SOGI data collection. This report builds on the knowledge gained from prior research done over the past ten years by subject matter experts including the Williams Institute, the Institute of Medicine, and the World Professional Association of Transgender Health (WPATH) and recommends four broadly tested measures for collecting information on SOGISC:

1. Which of the following best represents how you think of yourself? [Select ONE]:
 - a. Lesbian or gay;
 - b. Straight, that is, not gay or lesbian;
 - c. Bisexual;
 - d. [If respondent is AIAN:] Two-Spirit;
 - e. I use a different term [free-text]
 - f. Don't know
 - g. Prefer not to answer

2. What sex were you assigned at birth, on your original birth certificate?
 - a. Female
 - b. Male
 - c. Don't know
 - d. Prefer not to answer

³⁰ Advancing LGBT Health & Well-Being: 2016 Report, HHS LGBT Policy Coordinating Committee, U.S. Dep't of Health and Hum. Svcs. (2016), <https://www.hhs.gov/sites/default/files/2016-report-with-cover.pdf>.

³¹ Stern, Michael J., Stuart Michaels, Carolina Milesi, Melissa Heim Viox, and Heather Morrison, Medicare Current Beneficiary Survey (MCBS) Task 1.32.a: Develop and Test Sexual and Gender Minority Status (LGBT) Items, CMS OMH (2016).

³² See, e.g., Badgett, M.V. Lee, Kellan E. Baker, Kerith J. Conron, Gary J. Gates, Alison Gill, Emily Greytak, Jody L. Herman, et al., Best Practices for Asking Questions to Identify Transgender and Other Gender Minority Respondents on Population-Based Surveys (GenIUSS), Williams Institute at UCLA (2014), <https://williamsinstitute.law.ucla.edu/publications/geniuss-trans-pop-based-survey/>; Badgett, M.V. Lee, Naomi Goldberg, Kerith J. Conron, Gary J. Gates, et al., Best Practices for Asking Questions about Sexual Orientation on Surveys (SMART), Williams Institute at UCLA (2009), <https://williamsinstitute.law.ucla.edu/publications/smart-so-survey/>.



3. What is your current gender? [Mark only one]
 - a. Female
 - b. Male
 - c. Transgender
 - d. [If respondent is AIAN:] Two-Spirit;
 - e. I use a different term [free-text]
 - f. Don't know
 - g. Prefer not to answer

4. Have you ever been diagnosed by a medical doctor or other health professional with an intersex condition or a difference of sex development (DSD) or were you born with (or developed naturally in puberty) genitals, reproductive organs, or chromosomal patterns that do not fit standard definitions of male or female?
 - a. Yes
 - b. No
 - c. Don't know
 - d. Prefer not to answer³³

The practice of SOGISC demographic data collection is widely supported by LGBTQI and non LGBTQI-identifying individuals, subject-matter experts, CMS, and HHS. NASEM's new report highlights the feasibility of asking SOGISC questions in population-based surveys and health care settings. The report notes that the nonresponse rate for sexual orientation and identity questions on some of the largest national population surveys (such as NHIS, NRFSS, and the Census Household Pulse Survey) is incredibly low at under 3%, and the nonresponse rate for the two-step question on sex assigned at birth and gender are less than 1%.³⁴ CMS notes in its Equity Plan that collecting SOGISC data is part of a broader plan "for quality improvements and to address changes among the target populations over time."³⁵ CMS also notes the increased feasibility of collecting SOGISC data that new developments in health information technology have made possible.³⁶ Now that an expert consensus on SOGISC data collection guidelines has emerged in the form of the NASEM report, CMS should take this opportunity to put its equity plan into action by adopting the recommended measures. As CMS notes in its supporting statement that it will be necessary to engage in educational and technical

³³ NASEM Report, 7-12.

³⁴ *Id.*, at 55, 80.

³⁵ The CMS Equity Plan for Improving Quality in Medicare, CMS OMH, at 8 (Sept. 2015), https://www.cms.gov/About-CMS/Agency-Information/OMH/OMH_Dwnld-CMS_EquityPlanforMedicare_090615.pdf.

³⁶ *Id.*



assistance activities to support collection of race/ethnicity data, it will also be necessary for CMS to engage in educational activities to support collection of SOGISC data, test new questions, and ensure appropriate adjustments to language and terminology are made over time.

V. Collecting Disability Status Data

Along with race, ethnicity, SOGISC, and primary language, it is equally important that CMS engage in demographic data collection for people with disabilities. We strongly recommend this necessary step because of the wealth of information that already exists about barriers to care that people with disabilities routinely face. A recent CMS report recognizes that “[a]dults with disabilities are almost twice as likely to report unmet health care needs due to barriers they face in accessing care.”³⁷ Research has demonstrated that people with disabilities are less likely to receive clinical preventive services, at increased risk of developing preventable chronic conditions, and more likely to report challenges in accessing appropriate health care facilities, including physically accessible ones.³⁸ Allowing individuals to self-report disabilities at the enrollment level would better enable plans and entities to identify needs and allocate resources to address these issues as well as “enable examination of health services cost and utilization patterns for individuals with disabilities,”³⁹ yet Medicare does not currently routinely collect and report information about health care disparities or inequities for people with disabilities. This is especially shocking given that a significant portion of the Medicare-enrolled population has a disability: Approximately 16% of Medicare enrollees qualify on the basis of a disability, and an estimated 2 in 5 individuals over 65 in the United States report having a disability.⁴⁰

Similar to collection of preferred language data, we recommend comprehensive collection of disability status data so that plans can appropriately develop resources for enrollees who report accessibility needs as well as routinely monitor access and quality of care. Entities should be expected to use reported data to develop communication plans for those who may need sign language interpreters, large print or Braille written materials, or other auxiliary aids and services. As discussed above, information on disability status is critical for ensuring

³⁷ Improving Health Care for Adults with Disabilities: An Overview of Federal Data Sources, CMS OMH (2020), <https://www.cms.gov/files/document/federaldatadisability508.pdf>.

³⁸ Krahn, Gloria L, Deborah Klein Walker, and Rosaly Correa-De-Araujo, Persons with Disabilities as an Unrecognized Health Disparity Population, Am. J. Pub. Health (2015), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4355692/pdf/AJPH.2014.302182.pdf>.

³⁹ Improving Health Care for Adults with Disabilities: An Overview of Federal Data Sources, CMS OMH (2020), <https://www.cms.gov/files/document/federaldatadisability508.pdf>.

⁴⁰ Disability Impacts All of Us, CDC.gov (2020), <https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html>



accessibility to physical spaces where enrollees will receive care. Having comprehensive disability status data will assist plans understand the scope of the populations they serve and the prevalence of specific disability-related needs in their enrollees.

It should be an expectation that plans routinely collect disability data and provide these services to enrollees in order to address structural inequities—in terms of physical access, policies, and treatment—that lead to poor health access and outcomes for people with disabilities. We recommend that CMS add questions on the enrollment form that capture data about people with disabilities, starting with the six-question series that is used on the American Community Survey, CAPHS, MCBS, and other national surveys.⁴¹ The measures used on these surveys include questions were included in HHS' 2011 Data Collection Standards because they capture information on a range of disabilities, including:

1. Are you deaf or do you have serious difficulty hearing?
 - a. Yes
 - b. No

2. Are you blind or do you have serious difficulty seeing, even when wearing glasses?
 - a. Yes
 - b. No

3. Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions? (5 years old or older)
 - a. Yes
 - b. No

4. Do you have serious difficulty walking or climbing stairs? (5 years old or older)
 - a. Yes
 - b. No

5. Do you have difficulty dressing or bathing? (5 years old or older)
 - a. Yes
 - b. No

6. Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping? (15 years old or older)
 - a. Yes

⁴¹ Disability Datasets: Population Surveys that Include the Standard Disability Questions, CDC.gov (2020), <https://www.cdc.gov/ncbddd/disabilityandhealth/datasets.html>



b. ___No

We also recommend that CMS engage in testing of additional questions that capture information about an individual's communication abilities, psychological disabilities, learning disabilities, and autism.⁴²

For the same reason that we recommend adding SOGISC questions to the MA and PDP enrollment form, we urge CMS to begin collecting disability data. Survey data simply cannot capture the health disparities that occur within the health system at the same level of accuracy as enrollment data. Survey data also cannot facilitate meeting the functional and access needs of individual enrollees, which is especially salient for people with disabilities. Capturing data about an enrollee's disabilities on the enrollment form allows plans to share individual accessibility needs with providers, plan for physical accessibility needs, and thereby begin to remove some of the barriers that people with disabilities face. It also allows plans to share utilization data across various disability categories, allowing CMS to better monitor quality of care.

VI. Conclusion

We appreciate the opportunity to provide comments on the Medicare MA and PDP Model Enrollment Form. For questions or follow up on these comments, please reach out to Staff Attorney Charly Gilfoil at gilfoil@healthlaw.org.

Sincerely,



Elizabeth G. Taylor
Executive Director

⁴² See Morris, Megan A., Bonnielin K. Swenor, Silvia Yee, Closing Disability Disparities: EHR Data as First Step, Office of the Nat'l Coordinator for Health Information Technology (Mar. 1, 2022), https://www.healthit.gov/sites/default/files/facas/2022-03-01_Documenting_disability_brief.pdf.

