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June 6, 2022

Submitted via Regulations.gov

William N. Parham
Director, Paperwork Reduction Staff
Office of Strategic Operations and Regulatory Affairs
Centers for Medicare & Medicaid Services
7500 Security Boulevard
Baltimore, MD 21244

RE: CMS-10440, Data Collection to Support Eligibility Determinations for Insurance Affordability Programs and Enrollment through Health Insurance Marketplaces, Medicaid, and Children's Health Program Agencies

Dear Director Parham,

The National Health Law Program (NHeLP), founded in 1969, protects and advances the health rights of low-income and underserved individuals and families by advocating, educating, and litigating at the federal and state levels. NHeLP has long advocated for increased commitment to health equity and culturally and linguistically appropriate, accessible care. NHeLP appreciates the opportunity to provide feedback on the streamlined Health Insurance Marketplace and Insurance Affordability Programs Application Form (hereinafter "Application"). We write to urge CMS to follow through on its commitment to health equity by adopting broader demographic data collection on the Application.

Our comments address the need for expanded demographic data collection on the Application as a first and critical step to understand the health needs of discrete communities. CMS's

recently released Framework for Health Equity 2022-2032 prioritizes expanded demographic data collection in CMS programs for this reason: health care professionals, policymakers, and other stakeholders must first be able to identify populations facing health disparities before they can develop effective solutions.¹ Health status and health care utilization disparities persist, and in some cases have widened across many demographic variables 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. CMS has the tools to implement additional demographic data collection on the Application and should not wait any longer to use them.

I. General Recommendations

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. Data on smaller populations is often not extensive enough to lend itself to meaningful analysis.² For example, indigenous populations are often “rolled up” into one large category, obscuring the unique issues that different tribes face.³ Similarly, data is often not available for intersecting sub-populations that might experience multiple barriers to access.⁴

Despite years of consensus on the need for improved demographic data collection among CMS, HHS, and expert health and medical associations such as the Joint Commission,⁵

¹ Centers for Medicare and Medicaid Services, *CMS Framework for Health Equity 2022-2032* 12 (2022), <https://www.cms.gov/files/document/cms-framework-health-equity.pdf>.

² Victor Rubin et al., PolicyLink, *Counting a Diverse Nation: Disaggregating Data on Race and Ethnicity to Advance a Culture of Health 20-22* (2018), https://www.policylink.org/sites/default/files/Counting_a_Diverse_Nation_08_15_18.pdf.

³ *Id.* at 21.

⁴ *Id.*, and see Farah Kader et al., *Disaggregating Race/Ethnicity Data Categories: Criticisms, Dangers, and Opposing Viewpoints*, HEALTH AFF. FOREFRONT (Mar. 25, 2022), <http://healthaffairs.org/do/10.1377/forefront.20220323.555023>.

⁵ See The Joint Commission, *R3 Report: Patient-centered communication standards for hospitals* (Feb. 9, 2011), <https://www.jointcommission.org/-/media/tjc/documents/standards/r3-reports/r3-report-issue-1-20111.pdf>.



Institutes of Medicine,⁶ AMA⁷, NAIC,⁸ AHIP,⁹ and the public,¹⁰ uniform and comprehensive demographic data collection in federally-funded health programs has not been consistent.

CMS should use this opportunity to revise the Application and add more detailed demographic questions. 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 evaluate the options provided for race and ethnicity while revising the Application. Second, CMS should add questions that capture sex characteristics, sexual orientation, gender identity, and disability as recommended by an abundance of research by subject-matter experts. The recently released National Academies of Sciences, Engineering, and Medicine (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.¹¹ Third, while we recognize the Application currently includes one disability status question, we do not believe this is sufficient. CMS should add additional validated disability questions that appropriately capture a broader scope of mental and functional status. In addition to the six-question series on disability and functional status that is already part of HHS's data collection practices, CMS should evaluate new opportunities to capture information on enrollees' communication, learning, and psychological disabilities.

⁶ See Cheryl Ulmer et al., Institute of Medicine, *Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement*, (2009), <https://www.ahrq.gov/sites/default/files/publications/files/iomracereport.pdf>.

⁷ See Am. Med. Assoc., *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>; Am. Med. Assoc., *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>.

⁸ See Nat'l Assoc. of Insurance Commissioners, *Draft Principles for Data Collection* (Dec. 3, 2021), https://content.naic.org/cmte_ex_race_and_insurance.htm.

⁹ See AHIP, *AHIP Comments on OMB Racial Equity RFI 6-10* (Jul. 2, 2021), <https://www.ahip.org/documents/comment-letters/AHIP-Response-to-OMB-Equity-RFI-July-2021.pdf>.

¹⁰ See, e.g., Baker 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/>.

¹¹ Nancy Bates et al., Nat'l Academies of Sciences, Engineering, and Medicine, *Measuring Sex, Gender Identity, and Sexual Orientation* (2022), <https://www.nap.edu/read/26424/chapter/1> (hereafter, "NASEM Report").



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

a. Collect comprehensive demographic data beyond race, ethnicity, and binary sex

As we detail in parts II, III, and IV below, we urge CMS to collect demographic information on the Application to increase the understanding of health disparities faced by underserved populations. CMS must not only collect information about enrollees' race, ethnicity, and binary sex,¹² but also their preferred language, gender identity, sexual orientation, sex characteristics, and disability status. 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.¹³ We support CMS' stated goal of soliciting additional community feedback to revise the Application form.¹⁴ We encourage CMS to look for ways to incorporate regular stakeholder feedback in its data collection efforts. Regular review

¹² The current "sex" question allows enrollees to self-identify as male or female, but does not indicate whether the question measures sex assigned at birth or current gender. This may be helpful for assisting plans and programs with how to refer to the enrollee (i.e., "Ms." or "Mr."), but does not accurately measure sex and gender as a demographic identifier. It also may confuse enrollees whose gender marker on identity documents is mismatched.

¹³ Karen Wang et al., *Centering Equity in the Design and Use of Health Information Systems: Partnering with Communities on Race, Ethnicity, and Language Data*, HEALTH AFF. (May 19, 2021), <https://www.healthaffairs.org/doi/10.1377/forefront.20210514.126700/full/>.

¹⁴ Centers for Medicare and Medicaid Services, *Supporting Statement for Data Collection to Support Eligibility Determinations for Insurance Affordability Programs and Enrollment through Health Insurance Marketplaces, Medicaid, and Children's Health Insurance Program Agencies (CMS 10440)* (Apr. 6, 2022); and see Centers for Medicare and Medicaid Services, *Framework for Health Equity 2022-2032* 19 (2022), <https://www.cms.gov/files/document/cms-framework-health-equity.pdf>.



of responses and community input can ensure that response options are valid and representative of the general population.¹⁵

c. Ensure information is self-reported

We urge CMS to make clear on the Application that individual responses to demographic questions are strictly voluntary and should be self-reported to ensure accuracy. CMS recognizes the need to conduct education and training to be able to engage enrollees on the importance of providing this information. However, this education and training should also emphasize that the individual enrollee shall not be penalized for failing to provide demographic information on the Application.

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

CMS must provide appropriate education and technical support for Navigators, enrollment agents and brokers, and Exchange call center staff to be able to implement this new data collection accurately. Many may worry that asking these questions causes discomfort or offense, contributes to discrimination, or jeopardizes patient privacy.¹⁶ Yet, research shows broad support for the collection of race/ethnicity,¹⁷ disability status,¹⁸ and sexual orientation, gender identity, and sex characteristics (SOGISC) data¹⁹ to address disparities. We recommend that CMS provide front-line and enrollment staff with resources to explain why

¹⁵ See Victor Rubin et al., PolicyLink, *Counting a Diverse Nation: Disaggregating Data on Race and Ethnicity to Advance a Culture of Health* 24-26 (2018),

https://www.policylink.org/sites/default/files/Counting_a_Diverse_Nation_08_15_18.pdf.

¹⁶ Romana Hasnain-Wynia et al., The Commonwealth Fund, *Who, When, and How: The Current State of Race, Ethnicity, and Primary Language Data Collection in Hospitals, Health Research and Educational Trust* (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.

¹⁷ Baker 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/>.

¹⁸ Disability Rights Education and Defense Fund, *Issue Brief: The Case for Including Functional Limitation Measures in Electronic Health Records* (Mar. 2016), <https://dredf.org/wp-content/uploads/2012/07/Issue-Brief-Electronic-Health-Records-April-2016.pdf>.

¹⁹ 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*, PLOS ONE (2014), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4157837/pdf/pone.0107104.pdf>.



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.²⁰

We also suggest that CMS conduct additional research on 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.²¹ More recent research provides updated recommendations for demographic data collection in an application or administrative setting.²² CMS should review the literature and determine the best ways to request this information on applications, particularly when individuals apply in person or over-the-phone. This information would also be relevant for training the staff – Navigators, 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

²⁰ See Chris Grasso et al., *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>.

²¹ Am. Hospital Assoc., *Health Research and Educational Trust Disparities Toolkit*, AHA Institute for Diversity and Health Equity (2007), <https://ifdhe.aha.org/hretdisparities/toolkit>.

²² See Colin Planalp, State Health & Value Strategies, *New York State of Health Pilot Yields Increased Race and Ethnicity Question Response Rates* (2021), <https://www.shvs.org/new-york-state-of-health-pilot-yields-increased-race-and-ethnicity-question-response-rates/> (last visited May 27, 2022); Ruben D. Vega Perez et al., *Improving Patient Race and Ethnicity Data Capture to Address Health Disparities: A Case Study From a Large Urban Health System*, 14 *Cureus* 1 (2022), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8815799/pdf/cureus-0014-00000020973.pdf>.



care.²³ Similarly, capturing primary language of all applicants 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. 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 consequences, redlining, or targeting of specific groups. Policies must enable individuals to feel comfortable disclosing personal information without fear of discrimination.²⁴ We encourage CMS to protect the privacy of demographic data consistent with the standards set forth in ACA Section 3101, which built upon the privacy protections required by HIPAA. This includes providing sufficient resources and outreach to make individuals aware of their privacy protections and rights, help them understand why demographic data is important, and explain who will have access to which forms of information.

II. Collecting Race and Ethnicity Data

We strongly support CMS' decision to collect race and ethnicity demographic information on the Application. As CMS refocuses on health equity, CMS should continue to evaluate how it collects information on race and ethnicity to ensure that discrete populations are identified in data collection efforts.

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

²³ Disability Rights Education and Defense Fund, *Issue Brief: The Case for Including Functional Limitation Measures in Electronic Health Records* (Mar. 2016), <https://dredf.org/wp-content/uploads/2012/07/Issue-Brief-Electronic-Health-Records-April-2016.pdf>.

²⁴ See, e.g., Stella S. Yi et al., *The Mutually Reinforcing Cycle of Poor Data Quality and Racialized Stereotypes That Shapes Asian American Health*, HEALTH AFF. (Feb. 2022), <https://www.healthaffairs.org/doi/10.1377/hlthaff.2021.01417>.



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.²⁵ To avoid confusion, we suggest phrasing the question as, “what is your race/ethnicity?” 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.

Second, CMS should review and revise the response options to add more subcategories for Latino, Asian American, Native Hawaiian, Pacific Islander, and Middle Eastern and North African populations. Disaggregation of categories can “reveal subgroup differences that lead to more appropriate strategies to improve the health of different subgroups.”²⁶ For example, although cancer is the leading cause of death among Asian Americans, heart disease is the leading cause of death among Indian Americans, yet both populations are often considered together under the banner term “Asian.”²⁷ 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. This will enable future study of additional response options.

Third, CMS should require states who use their own application forms to use, at minimum, the response options that it provides on the Application in order to ensure uniformity of data collected. If a state chooses to use additional response options –which should be encouraged – the additional options should be able to “roll up” into the minimum categories provided by CMS. Response options should be uniform on both paper and electronic applications. Data collection loses its value and effectiveness where results cannot be compared.

²⁵ Rachel Marks and Nicholas Jones, U.S. Census Bureau, *Collecting and Tabulating Ethnicity and Race Responses in the 2020 Census* (Feb. 2020), <https://www2.census.gov/about/training-Vworkshops/2020/2020-02-19-pop-presentation.pdf>; and see Colin Planalp, New York State of Health Pilot Yields Increased Race and Ethnicity Question Response Rates, *State Health & Value Strategies* (2021), <https://www.shvs.org/new-york-state-of-health-pilot-yields-increased-race-and-ethnicity-question-response-rates/>. D’Vera Cohn et al., Pew Research Center, *Only about half of Americans say Census questions reflect their identity well* (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/>.

²⁶ Stella S. Yi et al., *The Mutually Reinforcing Cycle of Poor Data Quality and Racialized Stereotypes That Shapes Asian American Health*, *HEALTH AFF.* (Feb. 2022), <https://www.healthaffairs.org/doi/10.1377/hlthaff.2021.01417>.

²⁷ *Id.*



Finally, CMS should establish a revision process for the standardized language used on the Application 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.

III. Collecting Primary Language Data

LEP individuals face intersecting barriers in access and face demonstrated inequities in health outcomes. Because LEP individuals are more likely to be uninsured, CMS must ensure special attention is given so that LEP populations can be served equitably.²⁸

In order to determine informed remedies, we strongly recommend that CMS either modify its primary language question to ensure that it collects information on all individuals in the household who are LEP or add a new question to collect language data from all applicants. The Application includes a fill-in response where the household contact indicates their preferred written and spoken language. This question does not sufficiently measure the primary language used by each enrollee, and it is unclear whether the question captures primary language as a demographic identifier. If the Application only captures the primary language of the household contact, the Application fails to count how many enrollees are LEP. As noted in our above recommendations, identifying LEP enrollees enables CMS to track disparities and target solutions that address inequities in access. LEP enrollees are less likely to have a regular health care provider, have fewer physician visits, and lower rates of preventive screening.²⁹ 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 enrollees' 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

²⁸ Andriana M. Foiles Sifuentes et al., *The Role of Limited English Proficiency and Access to Health Insurance and Health Care in the Affordable Care Act Era*, 4 HEALTH EQUITY 509 (Dec. 2020), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7757700/>.

²⁹ *Id.*



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.³⁰ 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.³¹ 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.³² 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 Application. The resources, research, and information needed to support population-wide SOGISC data collection already exist in the work done by HHS by its

³⁰ See Gay and Lesbian Med. Assoc., *Healthy People 2010: Companion Document for Lesbian, Gay, Bisexual, and Transgender (LGBT) Health*, (2001), https://www.gлма.org/data/n_0001/resources/live/HealthyCompanionDoc3.pdf.

³¹ See 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*, PLOS ONE (2014), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4157837/pdf/pone.0107104.pdf>.

³² See, e.g., Nat'l Ctr. For Transgender Equality, *2015 U.S. Transgender Survey*, (2016), <https://www.ustranssurvey.org/reports>; Lambda Legal, *When Health Care Isn't Caring* (2010), https://www.lambdalegal.org/sites/default/files/publications/downloads/whcic-report_when-health-care-isnt-caring.pdf.



2016 LGBT Policy Coordinating Committee³³ and CMS in its 2016 Medicare Current Beneficiary Survey study,³⁴ as well as by private groups seeking to understand LGBTQI health.³⁵

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

³³ HHS LGBT Policy Coordinating Committee, *Advancing LGBT Health & Well-Being: 2016 Report* (2016), <https://www.hhs.gov/sites/default/files/2016-report-with-cover.pdf>.

³⁴ Michael J. Stern et al., CMS OMH, *Medicare Current Beneficiary Survey (MCBS) Task 1.32.a: Develop and Test Sexual and Gender Minority Status (LGBT) Items* (2016).

³⁵ See, e.g., Lee Badgett et al., Williams Institute at UCLA, *Best Practices for Asking Questions to Identify Transgender and Other Gender Minority Respondents on Population-Based Surveys (GenIUSS)* (2014), <https://williamsinstitute.law.ucla.edu/publications/geniuss-trans-pop-based-survey/>; Lee Badgett et al., Williams Institute at UCLA, *Best Practices for Asking Questions about Sexual Orientation on Surveys (SMART)* (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 answer³⁶

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 administrative settings, population-based surveys, and clinical 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%.³⁷ In addition, HRSA currently requires Health Center Programs to ask patients for information on their sexual orientation, gender identity, and sex assigned at birth.³⁸ Data

³⁶ NASEM Report, 7-12.

³⁷ *Id.*, at 55, 80.

³⁸ Health Resources & Svcs. Admin., *Health Center Program UDS Data, Table 3B: Demographic Characteristics*, data.HRSA.gov (2019), <https://data.hrsa.gov/tools/data-reporting/program-data/national/table?tableName=3B&year=2019>.



reported since 2019 shows that a majority of patients respond to SOGI questions.³⁹ Research indicates that with patient assistance and staff training, nonresponse rates diminish further.⁴⁰

CMS noted in its 2015 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.”⁴¹ CMS reiterated this commitment in its recent Framework for Health Equity 2022-2032. CMS also noted the increased feasibility of collecting SOGISC data that new developments in health information technology have made possible.⁴² 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 plans into action by adopting the recommended measures. 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.”⁴³ 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.⁴⁴

³⁹ *Id.*

⁴⁰ 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*, PLOS ONE 7 (2014), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4157837/pdf/pone.0107104.pdf>.

⁴¹ CMS OMH, *The CMS Equity Plan for Improving Quality in Medicare 8* (Sept. 2015), https://www.cms.gov/About-CMS/Agency-Information/OMH/OMH_Dwnld-CMS_EquityPlanforMedicare_090615.pdf.

⁴² *Id.*

⁴³ CMS OMH, *Improving Health Care for Adults with Disabilities: An Overview of Federal Data Sources* (2020), <https://www.cms.gov/files/document/federaldatadisability508.pdf>.

⁴⁴ Gloria L Krahn et al., *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>.



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.”⁴⁵ Yet the question on the current Application falls short of facilitating demographic identification or accessibility needs. The current Application asks a compound question that seeks to broadly identify whether the enrollee or household member has a disability. It does not allow the enrollee to select what type of disability the enrollee has, limiting the potential for accessibility planning in further interactions with the enrollee or household member.

Similar to collection of preferred language data, we recommend comprehensive collection of disability status data so that plans can appropriately develop resources and accommodations for enrollees who report accessibility needs as well as routinely monitor access and quality of care. Entities who receive enrollment information 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 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 and insurance affordability programs routinely collect self-reported 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 Application 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.⁴⁶ 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?

⁴⁵ CMS OMH, *Improving Health Care for Adults with Disabilities: An Overview of Federal Data Sources*(2020), <https://www.cms.gov/files/document/federaldatadisability508.pdf>.

⁴⁶ Ctrs. for Disease Control, *Disability Datasets: Population Surveys that Include the Standard Disability Questions*, CDC.gov (2020), <https://www.cdc.gov/ncbddd/disabilityandhealth/datasets.html>.



- 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
 - b. No

In addition to the above, CMS should consider testing additional questions that capture information about an individual's communication abilities, psychological disabilities, learning disabilities, and autism.⁴⁷

For the same reason that we recommend adding SOGISC questions to the Application, we urge CMS to begin collecting disability data for Marketplace plans. 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 and insurance affordability programs 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

⁴⁷ See Megan Morris et al., Office of the Nat'l Coordinator for Health Information Technology, *Closing Disability Disparities: EHR Data as First Step* (Mar. 1, 2022), https://www.healthit.gov/sites/default/files/facas/2022-03-01_Documenting_disability_brief.pdf.



also allows plans and programs to share utilization data across various disability categories, allowing CMS to better monitor quality of care for discrete groups.

VI. Conclusion

Thank you for the opportunity to comment on this important issue. Our comments include citations to supporting research and documents for the benefit of CMS in reviewing our comments. We direct CMS to each of the items cited and made available to the agency through active hyperlinks, and we request that CMS consider these, along with the full text of our comments, part of the formal administrative record on this proposed rule. For more information on our comments, please contact Staff Attorney Charly Gilfoil at gilfoil@healthlaw.org.

Sincerely,



Elizabeth G. Taylor
Executive Director

