NATIONAL HEALTH LAW PROGRAM

Submitted via Regulations.gov

August 16, 2023

Administrator Chiquita Brooks-LaSure
Centers for Medicare & Medicaid Services
Department of Health and Human Services
7500 Security Boulevard
Baltimore, MD 21244

RE: CMS-1500 and CMS-1490 S, Health Insurance Common Claims Form and Supporting Regulations at 42 CFR Part 424, Subpart C

Dear Administrator Brooks-LaSure:

The National Health Law Program (NHeLP) is a public interest law firm that works to advance equitable access to health care and protect the health rights of people with low incomes and underserved populations. For over fifty years, we have advocated, educated, and litigated at the federal and state levels to advance health and civil rights in the United States. Consistent with our mission, NHeLP has long advocated for more comprehensive demographic data collection to advance health equity, reduce discrimination, and facilitate the provision of equitable health care. We appreciate the opportunity to comment on the Health Insurance Common Claims Form (hereinafter “Form CMS-1500”) and write to urge CMS to adopt demographic data collection on Form CMS-1500.

Our comments address the importance of demographic data collection as a first and critical step towards advancing health equity. Only by collecting demographic data can CMS, health care providers, health plans, and other stakeholders begin to understand the health needs of discrete communities, identify and track health disparities, and develop targeted strategies to address inequities in outcomes and access. Demographic data collection also enables improved civil rights enforcement and facilitates person-centered planning in health care delivery. Therefore, NHeLP recommends CMS follow through on its commitment to health equity by adopting race and ethnicity data collection on Form CMS-1500. Our comments provide specific principles to guide demographic data collection through Form CMS-1500 and similar forms. NHeLP also encourages CMS to consider how tying data completion to reimbursement, financial incentives, and non-financial incentives can improve demographic data quality.

I. Adding Race and Ethnicity Demographic Fields to Form CMS-1500 Advances Health Equity

CMS acknowledges the importance of demographic data collection to achieving health equity in its Framework for Health Equity 2022-2032.[1] Priority 1 of CMS's Framework for Health Equity is to "Expand the Collection, Reporting, and Analysis of Standardized Data."[2] Priority 1 acknowledges that CMS programs must collect patient-reported demographic information to understand whether its programs provide equitable access to care for all eligible participants, and particularly those from underserved communities. Medicare, Medicaid, and many private insurers use Form CMS-1500 as a streamlined way to report patient data and claims information from providers. As such, CMS should take this opportunity to influence and advance patient-reported demographic data collection by adding race and ethnicity demographic fields to Form CMS-1500.[3]

CMS acknowledges that without demographic information on individuals served through its programs and activities, it cannot effectively understand equitable program access and service delivery. Yet, CMS also acknowledges the need to improve demographic data collection within its programs to achieve this goal.[4] Many providers already collect

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[1] Ctrs. for Medicare & Medicaid Servs., *CMS Framework for Health Equity 2022-2032* 12 (2022), https://www.cms.gov/files/document/cms-framework-health-equity.pdf. [Framework for Health Equity]

[2] Framework for Health Equity at 10.

[3] Although CMS-1500 is primarily used by providers, our comments include recommendations about how CMS should guide providers and other health care entities to adopt patient-reported demographic data collection practices.

[4] Framework for Health Equity at 10.

demographic information from their patients, including data on race, ethnicity, and languages written or spoken. Many also collect, or are beginning to adopt collection of, data on sexual orientation, gender identity, disability status, and other demographic characteristics. We recommend that CMS should immediately adopt a clear requirement to collect race and ethnicity of patients on Form CMS-1500 and add other demographic fields as they become more widely collected. Taking this first step now would improve understanding of population health, expose disparities that reflect systemic racism, improve civil rights enforcement, facilitate person-centered planning in health care delivery, and reach toward the goal of health equity.

Collection, analysis, and access to comprehensive demographic data across federally supported health insurance programs is essential for CMS, as well as health care professionals, policymakers, and other stakeholders, to be able to understand differences in population health as well as 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 and 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.

Demographic data is also increasingly necessary to protect the civil rights of individuals enrolled in or attempting to access CMS programs. Only by understanding who uses each program can CMS ensure that groups of people with different experiences—and particularly members of historically underserved populations—have equitable access and are served equitably. Having data on hand is an essential and straightforward way to ensure and demonstrate compliance with the requirements of § 1557 and other civil rights laws. As one example, data on COVID-19 treatment and outcomes disaggregated by race and ethnicity brought to light stark disparities in access to care faced by Black, Indigenous, and other People of Color (BIPOC) during the COVID-19 pandemic.[5] Even more importantly, accessing

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[5] Sebastian D. Romano et al., Ctrs. for Disease Control, *Trends in Racial and Ethnic Disparities in COVID-19 Hospitalizations, by Region – United States, March-December 2020*, 70 MORBIDITY & MORTALITY WEEKLY REPORT 560 (Apr. 16, 2021), https://www.cdc.gov/mmwr/volumes/70/wr/mm7015e2.htm.

this data leads to interventions to redress these disparities.[6] Yet, health data stratified by race and ethnicity remains incomplete or inadequate for subgroups, as well as for demographic categories beyond race and ethnicity, despite overwhelming evidence that these underserved groups historically face health barriers at higher rates than the general public.[7]

Finally, improving demographic data collection and availability across CMS programs improves CMS's ability—as well as the ability of providers, plans, and other entities—to plan for person-centered care. With access to broader race and ethnicity information from patient records, providers, plans, and programs can better understand the cultural and linguistic needs of their patient populations and ensure the availability of competent providers, program outreach, and public education materials.[8]

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[6] *See, e.g*., U.S. Dep't Health & Hum. Servs., *HHS Initiatives to Address the Disparate Impact of COVID-19 on African Americans and Other Racial and Ethnic Minorities* (2020), https://www.hhs.gov/sites/default/files/hhs-fact-sheet-addressing-disparities-in-covid-19-impact-on-minorities.pdf.

[7] *See* Medicaid & CHIP Payment & Access Comm'n, *Medicaid Race and Ethnicity Data Collection and Reporting: Recommendations for Improvement, in* March 2023 Report to Congress on Medicaid and CHIP (Mar. 2023), https://www.macpac.gov/wp-content/uploads/2023/03/Chapter-1-Medicaid-Race-and-Ethnicity-Data-Collection-and-Reporting-Recommendations.pdf; *and see* Nat'l Acad. Scis., Eng'g & Med., *Understanding the Well-Being of LGBTQI+ Populations* 75-81 (Charlotte J. Patterson et al. eds., 2020), https://www.ncbi.nlm.nih.gov/books/NBK563325/pdf/Bookshelf_NBK563325.pdf *and* Bonnelin Swenor, *A Need for Disability Data Justice*, Health Aff. (Aug. 22, 2022), https://www.healthaffairs.org/content/forefront/need-disability-data-justice *and* Off. Disease Prevention & Health Promotion, *Healthy People 2030: People with Disabilities*, https://health.gov/healthypeople/objectives-and-data/browse-objectives/people-disabilities (last visited Sept. 12, 2022).

[8] The Department of Health and Human Services, Office of Minority Health developed National Standards for Culturally and Linguistically Competent Services (CLAS), which recommend collecting demographic data to inform service delivery. Many of the other standards rely on having good demographic data on the local and patient population, including tailoring health services and communications to the needs of the local population, recruiting a leadership and workforce that reflects the racial and ethnic makeup of the area, and educating providers and staff on culturally competent practices. Off. Minority Health, U.S. Dep't Health & Hum. Servs., *National Standards for Culturally & Linguistically Competent Services (CLAS) in Health and Health Care*, https://thinkculturalhealth.hhs.gov/assets/pdfs/EnhancedNationalCLASStandards.pdf (last visited Aug. 15, 2023).

II. Recommendations for Adding Race and Ethnicity to Form CMS-1500[9]

If CMS supports our recommendation to include collection of demographic data on Form CMS-1500, we recommend CMS undertake additional steps to ensure the collection is accurate, comprehensive, and equitable. Thus we offer the following recommendations for principles to guide demographic data collection through Form CMS-1500 (and in other situations where CMS require demographic data collection):

- ***Develop resources and toolkits for providers to use when collecting demographic data, including explanations why this data is being collected.*** The Health Research and Educational Trust (HRET) developed a toolkit for collecting race, ethnicity, and language data at hospital admissions after testing different rationales for collecting this data.[10] Additional research, including case studies of data collection implementation, informs strategies and best practices for collecting data across all demographic categories.[11] CMS should review these resources and case studies to develop recommendations, toolkits, and technical assistance for programs to engage in demographic data collection in different situations (*e.g.,* on applications, by insurers, during admissions at covered entities, during healthcare encounters).

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[9] In this comment, we recommend adopting race and ethnicity data collection on Form CMS-1500. However, we support CMS broadening its demographic data collection to race, ethnicity, sex, sexual orientation, gender identity, sex characteristics (including intersex status), and disability as well. We encourage CMS to adopt broader demographic data collection in its program administration generally. *See* Nat'l Health L. Prog. Comments on Section 1557 Proposed Rule (Oct. 22, 2022), https://healthlaw.org/resource/nhelp-comments-on-section-1557-proposed-rule/.

[10] *See* Am. Hosp. Ass'n, *AHA Disparities Toolkit*, http://www.hretdisparities.org (last visited Sept. 12, 2022).

[11] *See* 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/; Colin Planalp, State Health Access Data Assistance Ctr. (SHADAC), *New York State of Health Pilot Yields Increased Race and Ethnicity Question Response Rates*, State Health & Value Strategies (Sept. 9, 2021), https://www.shvs.org/new-york-state-of-health-pilot-yields-increased-race-and-ethnicity-question-response-rates/; Elizabeth Lunkanen & Emily Zylla*, Exploring Strategies to Fill Gaps in Medicaid Race, Ethnicity, and Language Data*, State Health Access Data Assistance Ctr. (SHADAC) (2020), https://www.shvs.org/exploring-strategies-to-fill-gaps-in-medicaid-race-ethnicity-and-language-data/.

- ***Adopt clear privacy and nondiscrimination protections.*** For a data collection requirement to be impactful, individuals must feel comfortable disclosing personal information that can help to improve the care they receive and foster a broader understanding of health care disparities. In light of targeted state attacks against people from distinct marginalized communities, we encourage CMS to clarify how the privacy protections in the Health Insurance Portability and Accountability Act (HIPAA) of 1996 as well as other federal and state laws apply to demographic data collected by the agency and its proxies. CMS should ensure that individuals are made aware of their privacy protections and rights, the reason this information is being collected, who will have access to what forms of information, and how this information will be shared.

- ***Safeguard that reporting of demographic data be voluntary and self-reported.*** While entities should be required to input patient-reported demographic information (and for minors or incapacitated individuals, through a proxy), the responses to data collection requests are (and should be) voluntary to report and should be self-reported to ensure accuracy.[12] Patient-reported demographic information remains the gold standard for understanding and responding to patient needs and demographic differences. CMS should develop and distribute comprehensive educational and training materials for staff who will be collecting demographic data from patients.[13]

- ***Set, review, and update standardized variables for each demographic category.*** Since 1977, OMB has instructed federal agencies to use specific variables when collecting information about race and ethnicity. In 2011, HHS set minimum standards for collecting data about race, ethnicity, sex, language, and disability (the 2011 Data Standards).[14] However, these requirements were limited to data collected from surveys only. HHS must set standardized variables for data collection across **all** of its programs and agencies, including CMS programs, whether for survey data, administrative data, or clinical data. OMB is currently in the process of updating its race and ethnicity statistical

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[12] *See* Jared Bullard, *Improving Collection of Self-Reported Race & Ethnicity Data*, RTI HEALTH ADVANCE (Nov. 29, 2022), https://healthcare.rti.org/insights/improving-collection-of-self-reported-race-and-ethnicity-data.
[13] *Id*.
[14] U.S. Dep't Health & Hum. Servs., *Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status* 8 (Oct. 30, 2011), https://aspe.hhs.gov/sites/default/files/migrated_legacy_files//43681/index.pdf.

standards found in Directive No. 15.[15] Once these standards are finalized, CMS should quickly adopt the new requirements to ensure consistency of race and ethnicity data collection across all of its programs***.***

- ***Support intersectional analyses based on multiple demographic variables.*** While we recommend several specific demographic variables for data collection to better ensure civil rights compliance, it should be emphasized that these variables are neither mutually exclusive nor unrelated. As individuals, each person has a sex, race, ethnicity, primary language, and disability status, and all these demographic identities interact in relevant ways for understanding and addressing health disparities. At the community and population level, these variables, both individually and in combination, can be explanatory for discrimination. For example, racial and ethnic minority women receive poorer quality care than racial and ethnic minority men, who receive poorer care than white men.[16] Spanish-speaking Latine individuals experience poorer quality care than English-speaking Latine individuals, who experience poorer care than non-Latine white individuals.[17] Compared to women without disabilities, women with disabilities are more likely not to receive regular mammograms or Pap tests.[18] Racial and ethnic minorities with disabilities experience greater disparities in diagnoses and utilization of assistive technology.[19] While discrimination investigation sometimes focuses on variations based

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[15] Off. Mgmt. & Budget, *Initial Proposals For Updating OMB's Race and Ethnicity Statistical Standards*, 88 Fed. Reg. 5375-5384 (Jan. 27, 2023), https://www.federalregister.gov/documents/2023/01/27/2023-01635/initial-proposals-for-updating-ombs-race-and-ethnicity-statistical-standards.

[16] Rosaly Correa de Araujo et al., *Gender differences across racial and ethnic groups in the quality of care for acute myocardial infarction and heart failure associated co-morbidities*, 16 WOMEN'S HEALTH ISSUES 44-56 (2006); Ann F. Chou et al., *Gender and racial disparities in the management of diabetes mellitus among Medicare patients*, 17 WOMEN'S HEALTH ISSUES 150-61 (2007).

[17] Eric M. Cheng et al., *Primary language and receipt of recommended health care among Hispanics in the United States*, 22 J. GEN. INTERN. MED. 283-88 (2007); C. Annette DuBard et al., *Language spoken and differences in health status, access to care and receipt of preventive services among U.S. Hispanics*, 98 AM. J. PUB. HEALTH 2021-28 (2008).

[18] Marguerite E. Diab & Mark V. Johnston, *Relationships between level of disability and receipt of preventive health services*, 85 ARCHIVES OF PHYSICAL MEDICINE & REHABILITATION 749-757 (2004).

[19] David S. Mandell et al., *Racial/ethnic disparities in the identification of children with autism spectrum disorders*, 99 AM. J. PUB. HEALTH 493-98 (2009); H. Stephen Kaye et al., *Disparities*

on a single demographic variable, it is vital that CMS's civil rights enforcement support intersectional analyses based on multiple demographic variables. This requires standardized categories and definitions for all these demographic variables.

- ***Conduct regular review and engage community 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.[20] We support the use of focus groups, listening sessions, and direct outreach for testing of data collection methods and community feedback to revise the data collection standards adopted. 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.

- ***Ensure public reporting of data and analysis***. For meaningful accountability, CMS must make the resulting data available and accessible by the public and by researchers. Delays and barriers result in less accountability and less public ownership and agency over data.

III. CMS Can Improve Demographic Data Quality by Tying Data Completion to Reimbursement, Financial Incentives, and Non-Financial Incentives

Leveraging incentives can introduce the element of accountability necessary to improve demographic data collection towards the goal of advancing health equity.[21] Various health care

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in usage of assistive technology among people with disabilities, 20 ASSIST. TECHNOL. 194-203 (2008).

[20] Stella S. Yi et al., *The Mutually Reinforcing Cycle of Poor Data Quality and Racialized Stereotypes that Shapes Asian American Health*, HEALTH AFFS. (Feb. 2022), https://www.healthaffairs.org/doi/10.1377/hlthaff.2021.01417; 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 AFFS. (2019), https://www.healthaffairs.org/do/10.1377/forefront.20210514.126700/.

[21] *See* Robin L. Pierce et al., *Tying Equity to Reimbursements*, HEALTH AFFS. FOREFRONT (Aug. 7, 2023), https://www.healthaffairs.org/content/forefront/reform-response-tying-equity-

stakeholders, including payers, providers, and purchasers, have recommended implementing incentives to create accountability for improved demographic data collection.[22] CMS has already implemented quality initiatives, such as value-based programs (VBP), that link data on quality of care to financial incentives and non-financial incentives like public reporting.[23] Further, CMS recently introduced an initiative to tie demographic data collection to health equity index rewards and health equity adjustments to VBP scoring for some participating Medicare hospital systems.[24] CMS should explore taking similar steps here to link

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reimbursements; Ava Ferguson Bryan et al., The Commonwealth Fund, *Advancing Health Equity Through Federal Payment and Delivery System Reforms* (Jun. 15, 2022), https://www.commonwealthfund.org/blog/2022/advancing-health-equity-through-federal-payment-and-delivery-system-reforms.

[22] *See* Health Care Transformation Task Force, *Building the Business Case for Health Equity Investment: Strategies to Secure Sustainable Support* (Jan. 2023), https://hcttf.org/wp-content/uploads/2023/01/HEAG-Business-Case-Full_Final.pdf; Purchaser Bus. Grp. on Health, *Improving the Collection and Use of Race, Ethnicity, and Language Data* (Oct. 2022), https://www.pbgh.org/wp-content/uploads/2022/10/Improving-the-Collection-and-Use-of-Race-Ethnicity-and-Language-Data.pdf; United HealthCare, *Health Equity in Medicaid Report: Challenges & Opportunities* (Nov. 11, 2022), https://www.uhccommunityandstate.com/content/topic-profiles/health-equity/our-commitment-to-health-equity-in-medicaid; Blue Shield Blue Cross Ass'n & Nat'l Minority Quality F., *Standardizing Data to Advance the Health Equity Movement: A Multi-Sectorial Strategy* (Mar. 28, 2023), https://www.bcbs.com/sites/default/files/healthequity/REL/NMQF_Brief_Paper.pdf.

[23] Ctrs. for Medicare & Medicaid Servs., *Value-Based Programs*, https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Value-Based-Programs/Value-Based-Programs; *see* William K. Bleser et al., *ACO REACH and Advancing Equity Through Value-Based Payment, Part 2*, HEALTH AFF. FOREFRONT (May 18, 2022), https://www.healthaffairs.org/content/forefront/reform-response-tying-equity-reimbursements.

[24] *See* Ctrs. for Medicare & Medicaid Servs., *Medicare Program; Contract Year 2024 Policy and Technical Changes to the Medicare Advantage Program, Medicare Prescription Drug Benefit Program, Medicare Cost Plan Program, and Programs of All-Inclusive Care for the Elderly*, 88 Fed. Reg. 22120-22345 (Apr. 12, 2023), https://www.federalregister.gov/documents/2023/04/12/2023-07115/medicare-program-contract-year-2024-policy-and-technical-changes-to-the-medicare-advantage-program; Ctrs. for Medicare & Medicaid Servs., *Medicare Program: Hospital Inpatient Prospective Payment Systems for Acute Care Hospitals and the Long Term Care Hospital Prospective Payment System and Policy Changes and Fiscal Year 2024 Rates, etc.* (scheduled to be published Aug. 28, 2023), https://www.federalregister.gov/public-inspection/2023-16252/medicare-program-hospital-inpatient-prospective-payment-systems-for-acute-care-hospitals-and-the.

demographic data reporting completeness on reimbursement forms to such incentives, with a strong emphasis and review to ensure that such steps still emphasize the need for patient-reported data. Because demographic data collection is a necessary first step to improving quality of care and advancing health equity, CMS should take this and other opportunities to consider how best to structure incentives to improve demographic data completion and quality.

IV. Conclusion

We appreciate the opportunity to provide comments on the CMS Form-1500. Our comments include citations to supporting research and materials for the benefit of CMS in reviewing our comments. We direct CMS to each of the items we have 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 for this information collection. For questions or further information on our comments, please contact Charly Gilfoil, Staff Attorney, at gilfoil@healthlaw.org and Michelle Yiu, Policy Fellow, at yiu@healthlaw.org.

Sincerely,

Elizabeth G. Taylor
Executive Director