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### Submitted via Regulations.gov

October 20, 2023

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

## **RE: Application for Enrollment in Medicare the Medical Insurance Program (CMS-40B)**

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 Application for Enrollment in Medicare the Medical Insurance Program (hereinafter "Form CMS-40B") and write to urge CMS to adopt demographic data collection on Form CMS-40B.

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 adopt demographic data collection fields on Form CMS-40B. Our comments provide specific principles to guide demographic data collection through Form CMS-40B and similar forms.

## I. Demographic Data on Medicare-Enrolled Individuals is Currently Inadequate to Inform Program Analysis and Decisionmaking

Although CMS collects and retains some demographic data for certain Medicare enrollees, the scope and quality of demographic data lacks consistency and usefulness to inform effective program administration. Adopting demographic data collection on the Form CMS-40B would give CMS an opportunity to obtain self-reported, comprehensive information on the majority of Medicare enrollees, transforming the agency's ability to understand who accesses the program.

Current demographic information on Medicare enrollees is limited. The Medicare program gathers a limited amount of information on enrollees' race and ethnicity through historical Social Security Administration (SSA) race and ethnicity data, algorithms that rely on individuals' last name and census tract to impute race or ethnicity, the Medicare Current Beneficiary Survey (MCBS), which relies on a sample of the Medicare-enrolled population, and most recently, the Medicare Part C and D Enrollment Form.<sup>1</sup>

<sup>&</sup>lt;sup>1</sup> U.S. Dep't of Health & Hum. Servs., Off. Inspector Gen., *Data Brief: Inaccuracies in Medicare's Race and Ethnicity Data Hinder the Ability To Assess Health Disparities* (Jun. 2022), <a href="https://oig.hhs.gov/oei/reports/OEI-02-21-00100.pdf">https://oig.hhs.gov/oei/reports/OEI-02-21-00100.pdf</a> [hereinafter OIG Report]; Ctrs. for Medicare & Medicaid Servs., *Agency Information Collection Activities: Submission for OMB Review; Comment Request*, 88 Fed. Reg. 40827 (Jun. 22, 2023), <a href="https://www.federalregister.gov/documents/2023/06/22/2023-13199/agency-information-collection-activities-submission-for-omb-review-comment-request">https://www.federalregister.gov/documents/2023/06/22/2023-13199/agency-information-collection-activities: Submission for OMB Review; Comment Request, 87 Fed. Reg. 26759 (May 5, 2022), <a href="https://www.federalregister.gov/documents/2022/05/05/2022-09685/agency-">https://www.federalregister.gov/documents/2022/05/05/2022-09685/agency-</a>



Despite these multiple sources, a 2022 report from the U.S. Department of Health and Human Services Office of the Inspector General (OIG) found that CMS's data on Medicare enrollees' race and ethnicity lacks accuracy, currentness, and completeness.<sup>2</sup> The report found that because SSA only allowed individuals to self-select "white," "Black," or "other" race, and Medicare uses that data in its system, Medicare has limited information on individuals of other races and ethnicities.<sup>3</sup> OIG also found that Medicare does not regularly, directly collect race and ethnicity information from enrollees to fill in those gaps; it instead relies on imputed information that more frequently misidentifies people who are Native American, Asian or Pacific Islander, and Hispanic or Latino.<sup>4</sup> Finally, OIG determined that Medicare data lacks completeness and cohesion with current federal data collection standards due to these gaps in self-reported data.<sup>5</sup> These gaps "inhibit the work of identifying and improving health disparities within the Medicare population."<sup>6</sup>

The OIG report's first recommendation is for CMS to develop its own source of demographic data on Medicare enrollees, such as through the initial Medicare enrollment form. We concur with the OIG's findings and recommendations and encourage CMS to adopt comprehensive demographic data collection on the Form CMS-40B, which reaches the vast majority of Medicare participants at enrollment.

# II. CMS Must Add Demographic Fields to the Form CMS-40B to Advance Health Equity

Adding demographic fields to the Form CMS-40B would improve the quality and completeness of demographic data collected by the Medicare program significantly more

<u>information-collection-activities-submission-for-omb-review-comment-request</u> (Model Medicare Part C and D Individual Enrollment Request Form).

<sup>&</sup>lt;sup>8</sup> The OIG Report also recommends that CMS use self-reported race and ethnicity information, develop a process to ensure data are as standardized as possible, and educate consumers about efforts to improve understanding of race and ethnicity in Medicare. OIG Report at 10-12.



<sup>&</sup>lt;sup>2</sup> OIG Report at 1.

<sup>&</sup>lt;sup>3</sup> *Id*. at 6.

<sup>&</sup>lt;sup>4</sup> *Id.* at 7-8.

<sup>&</sup>lt;sup>5</sup> *Id.* at 9.

<sup>&</sup>lt;sup>6</sup> *Id*. at 1.

<sup>&</sup>lt;sup>7</sup> OIG Report at 19.

the current methods outlined above and in the OIG Report. We encourage CMS to adopt demographic data collection on enrollees' race, ethnicity, written and spoken language, disability status, sexual orientation, gender identity, and sex characteristics in this version of the Form CMS-40B in addition to other demographic data collection it already has in place.

Although CMS recently added fields for data on enrollees' race and ethnicity on the Model Medicare Part C and D Enrollment Request Form (CMS-10718), this action does not go far enough to achieve quality, comprehensive, and granular demographic data on Medicare enrollees. For one, not every Medicare enrollee chooses to enroll in Part C or D.<sup>9</sup> By adding demographic data collection to the Form CMS-40B, CMS could reach over 90% of Medicare enrollees, approximately 59 million people, as compared to the approximately 51% of enrollees that sign up for Medicare Part C and 78% of enrollees that sign up for Part D.<sup>10</sup>

Further, CMS has more control over the information enrollees provide to sign up for Medicare Part B than it does enrollees who sign up for Part C and D. CMS partners with SSA to collect Part B enrollment information using the Form CMS-40B; CMS and SSA own responsibility for administering the form, providing instruction and guidance to enrollees, and storing and sharing the information collected. Comparatively, the Medicare Part C and D Enrollment Form is administered by the individual's selected Medicare Advantage or Prescription Drug Plan, which could be any number of different insurers, plans, or entities. Information from the Part C and D Enrollment Form goes through each individual insurer or plan's enrollment system before it ends up in CMS's enrollment database. Finally, an individual seeking to enroll in Medicare Part B will use the same enrollment form whether completed on site or SSA or off-site by the individual and returned to SSA.<sup>11</sup> In contrast,

<sup>&</sup>lt;sup>11</sup> See Ctrs. for Medicare & Medicaid Servs, Supporting Statement Part A: Application for Enrollment in Medicare Part B (Medical Insurance) at 1-2 (Aug. 23, 2023),



<sup>&</sup>lt;sup>9</sup> See Wafa Tarazi et al., Asst. Sec. for Planning & Evaluation, Off. of Health Policy, *Issue Brief: Medicare Beneficiary Enrollment Trends and Demographic Characteristics* (Mar. 2, 2022),

https://aspe.hhs.gov/sites/default/files/documents/f81aafbba0b331c71c6e8bc66512e25d/medicare-beneficiary-enrollment-ib.pdf.

<sup>&</sup>lt;sup>10</sup> *Id.*, and see Ctrs. for Medicare & Medicaid Servs., Access to Health Coverage <a href="https://www.cms.gov/pillar/expand-access">https://www.cms.gov/pillar/expand-access</a> (last visited Oct. 5, 2023).

CMS publishes the Part C and D Enrollment Form as a model, meaning insurers can modify the language, format, or order of the Part C and D enrollment form for their own use. 12 By adding demographic information to a form that CMS more directly administers, CMS has the ability to ensure more consistency in the data collection practices it uses and thus more likelihood of obtaining quality data. 13

Information obtained through the Medicare Current Beneficiary Survey, the National Health Interview Survey, and other national health surveys cannot be a substitute for information collected on each enrollee at enrollment. Individualized data on each enrollee "enables CMS and our stakeholders to address changes in populations over time and leverage information to connect individuals to appropriate and needed social services and supports," including providing accessibility and language access services for people with disabilities and limited English proficiency. Collecting data on each enrollee at initial enrollment also enables CMS to obtain a quantity of data that allows for disaggregation of granular and intersectional populations that typically go uncounted but who we know

https://www.cms.gov/regulations-and-guidance/legislation/paperworkreductionactof1995/pralisting-items/cms-40b.

<sup>&</sup>lt;sup>15</sup> Ctrs. for Medicare & Medicaid Servs., *CMS Framework for Health Equity 2022-2032* at 12 (2022), <a href="https://www.cms.gov/files/document/cms-framework-health-equity.pdf">https://www.cms.gov/files/document/cms-framework-health-equity.pdf</a> [hereinafter Framework for Health Equity].



<sup>&</sup>lt;sup>12</sup> See Ctrs. for Medicare & Medicaid Servs., Supporting Statement Part-A, Model Medicare Advantage and Prescription Drug Plan Individual Enrollment Request Form at 1 (Sept. 29, 2023), <a href="https://www.cms.gov/regulations-and-guidancelegislationpaperworkreductionactof1995pra-listing/cms-10718">https://www.cms.gov/regulations-and-guidancelegislationpaperworkreductionactof1995pra-listing/cms-10718</a>.

<sup>&</sup>lt;sup>13</sup> "Consistent and centralized data will allow for more comprehensive analyses and assessments of health disparities." OIG Report at 11.

<sup>&</sup>lt;sup>14</sup> See generally Lacey Hartman & Karen Turner, State Health Access Data Assistance Ctr. (SHADAC), Medicaid & CHIP Payment & Access Comm'n. (MACPAC), Federal Survey Sample Size Analysis: Disability, Language, and Sexual Orientation and Gender Identity (Sept. 14, 2023), <a href="https://www.macpac.gov/wp-content/uploads/2023/10/Federal-Survey-Sample-Size-Analysis-Disability-Language-and-Sexual-Orientation-and-Gender-Identity.pdf">https://www.macpac.gov/wp-content/uploads/2023/10/Federal-Survey-Sample-Size-Analysis-Disability-Language-and-Sexual-Orientation-and-Gender-Identity.pdf</a> (finding that sample sizes on various demographic populations from the MCBS and other federal surveys were too small to generate useable data).

experience severe disparities, such as smaller ethnic and multiracial populations, and LGBTQI+ people with disabilities.<sup>16</sup>

CMS acknowledges the importance of demographic data collection to achieving health equity in its response to the OIG report, and in doing so, reiterates its commitment "to obtain[] more accurate and comprehensive race and ethnicity data for people with Medicare." Further, HHS has charged CMS with incorporating demographic data collection on sexual orientation, gender identity, and sex characteristics data on program applications in its 2023 SOGI Data Action Plan. Including demographic data collection on the Form CMS-40B would allow CMS to follow through on its obligations to capture more accurate demographic information for the Medicare-enrolled population and to obtain a more complete picture of diversity of experiences within the Medicare program. <sup>18</sup>

### III. Recommendations for Adding Demographic Fields to the Part B Application

If CMS supports our recommendation to include collection of demographic data on Form CMS-40B, 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-40B (and in other situations where CMS require demographic data collection):

 Collect Demographic Data on Race, Ethnicity, Preferred Language, Disability, Sexual Orientation, Sex Characteristics, and Gender Identity. CMS and HHS have repeatedly acknowledged the need to collect demographic data on individuals' "race, ethnicity, language, gender identity, sex, sexual orientation, and disability status" to advance health equity. 19 Self-reported demographic information from the Form CMS-40B could transform the way we understand health care access and outcomes in Medicare for all groups. On the contrary, without this information, it will be difficult if not

<sup>&</sup>lt;sup>19</sup> Framework for Health Equity at 12; *and see* U.S. Dep't of Health & Hum. Servs., *HHS Equity Action Plan* at 2 (Apr. 2022), <a href="https://www.hhs.gov/sites/default/files/hhs-equity-action-plan.pdf">https://www.hhs.gov/sites/default/files/hhs-equity-action-plan.pdf</a>.



<sup>&</sup>lt;sup>16</sup> Charly Gilfoil, Julia Liou, & Thu Quach, *Advancing Health Equity Through Disaggregated Race/Ethnicity Data*, Leadership Conference for Civil & Hum. Rts. (Jul 28, 2023), <a href="https://civilrights.org/blog/advancing-health-equity-through-disaggregated-race-ethnicity-data/">https://civilrights.org/blog/advancing-health-equity-through-disaggregated-race-ethnicity-data/</a>.

<sup>&</sup>lt;sup>17</sup> OIG Report at 19; see also Framework for Health Equity at 12.

<sup>&</sup>lt;sup>18</sup> OIG Report at 19.

impossible for CMS to demonstrate change or improvement in health care quality among any of the populations named. As CMS acknowledges, "[r]eporting of stratified data is a cornerstone of our approach to advancing health equity."<sup>20</sup>

- 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).<sup>21</sup> However, these requirements were limited to data collected from surveys only. CMS must use standardized variables for data collection across all of its programs and agencies, including Medicare, whether for survey data, administrative data, or clinical data. OMB is currently in the process of updating its race and ethnicity statistical standards found in Directive No. 15.<sup>22</sup> 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. In addition, CMS should adopt the consensus recommendations from the National Academies of Sciences, Engineering, and Medicine on demographic data collection of sexual orientation, gender identity, and sex characteristics (SOGISC) in administrative, clinical, and survey settings.<sup>23</sup>
- Adopt Data Collection Practices While Continuing to Develop Standards. We are encouraged to see adoption of new demographic data collection in Medicare on the

<sup>&</sup>lt;sup>23</sup> Nancy Bates et al., National Academies of Sciences, Engineering, and Medicine, *Measuring Sex, Gender Identity, and Sexual Orientation* (2022), https://nap.nationalacademies.org/read/26424/chapter/1#x.



<sup>&</sup>lt;sup>20</sup> Ctrs. for Medicare & Medicaid Servs., *Medicaid Program and CHIP; Mandatory Medicaid and Children's Health Insurance Program (CHIP) Core Set Reporting*, 88 Fed. Reg. 60278, 60289 (Aug. 31, 2023), <a href="https://www.govinfo.gov/content/pkg/FR-2023-08-31/pdf/2023-18669.pdf">https://www.govinfo.gov/content/pkg/FR-2023-08-31/pdf/2023-18669.pdf</a>.

<sup>&</sup>lt;sup>21</sup> 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), <a href="https://aspe.hhs.gov/sites/default/files/migrated\_legacy\_files//43681/index.pdf">https://aspe.hhs.gov/sites/default/files/migrated\_legacy\_files//43681/index.pdf</a>.

<sup>&</sup>lt;sup>22</sup> 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.

Model Part C and D Enrollment Form and the Medicare Current Beneficiary Survey.<sup>24</sup> As with the Model Part C and D Enrollment Form, CMS should simultaneously begin collecting demographic data on the Form CMS-40B while continuing to test and develop new recommendations to improve demographic data collection and analysis. CMS should apply existing data collection recommendations, as discussed above, while using the feedback and results from cognitive testing to improve data quality.

Develop Resources and Toolkits for Agencies and Assisters 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.<sup>25</sup> Additional research, including case studies
 of data collection implementation, informs strategies and best practices for collecting
 data across all demographic categories.<sup>26</sup> CMS should review these resources and

<sup>&</sup>lt;sup>26</sup> 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) <a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8815799/">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8815799/</a>; 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), <a href="https://www.shvs.org/new-york-state-of-health-pilot-yields-increased-race-and-ethnicity-question-response-rates/">https://www.shvs.org/new-york-state-of-health-pilot-yields-increased-race-and-ethnicity-question-response-rates/</a>; Elizabeth Lunkanen & Emily Zylla, *Exploring Strategies to Fill Gaps in Medicaid Race, Ethnicity, and Language Data*, State Health Access Data Assistance Ctr. (SHADAC) (2020), <a href="https://www.shvs.org/exploring-strategies-to-fill-gaps-in-medicaid-race-ethnicity-and-language-data/">https://www.shvs.org/exploring-strategies-to-fill-gaps-in-medicaid-race-ethnicity-and-language-data/</a>; Nat'l LGBTQIA+ Health Education Ctr., Cultural Adaptation of



Ctrs. for Medicare & Medicaid Servs., Agency Information Collection Activities: Submission for OMB Review; Comment Request, 88 Fed. Reg. 40827 (Jun. 22, 2023), <a href="https://www.federalregister.gov/documents/2023/06/22/2023-13199/agency-information-collection-activities-submission-for-omb-review-comment-request">https://www.federalregister.gov/documents/2023/06/22/2023-13199/agency-information-collection-activities-submission-for-omb-review-comment-request</a> (Medicare Current Beneficiary Survey); Ctrs. for Medicare & Medicaid Servs., Agency Information Collection Activities: Submission for OMB Review; Comment Request, 87 Fed. Reg. 26759 (May 5, 2022), <a href="https://www.federalregister.gov/documents/2022/05/05/2022-09685/agency-information-collection-activities-submission-for-omb-review-comment-request">https://www.federalregister.gov/documents/2022/05/05/2022-09685/agency-information-collection-activities-submission-for-omb-review-comment-request</a> (Model Medicare Part C and D Individual Enrollment Request Form).

<sup>&</sup>lt;sup>25</sup> See Am. Hosp. Ass'n, *AHA Disparities Toolkit*, <a href="http://www.hretdisparities.org">http://www.hretdisparities.org</a> (last visited Sept. 12, 2022).

case studies to develop recommendations, toolkits, and technical assistance for agencies and assisters to help individuals understand the demographic data questions on the Form CMS-40B and increase the likelihood that individuals will respond.

- 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 (including state and local governments and private entities). 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 demographic information should be requested on Form CMS-40B for all respondents (and for 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. Self-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 assist individuals with completing the Form CMS-40B.28

Measures and Tools for Sexual Orientation and Gender Identity (SOGI) Data Collection, <a href="https://www.lgbtqiahealtheducation.org/courses/cultural-adaptation-of-measures-and-tools-for-sexual-orientation-and-gender-identity-sogi-data-collection/">https://www.lgbtqiahealtheducation.org/courses/cultural-adaptation-of-measures-and-tools-for-sexual-orientation-and-gender-identity-sogi-data-collection/</a> (last visited Sept. 7, 2023).

<sup>&</sup>lt;sup>28</sup> *Id.*; Elizabeth Lunkanen & Emily Zylla, *Exploring Strategies to Fill Gaps in Medicaid Race, Ethnicity, and Language Data*, State Health Access Data Assistance Ctr. (SHADAC) (2020), <a href="https://www.shvs.org/exploring-strategies-to-fill-gaps-in-medicaid-race-ethnicity-and-language-data/">https://www.shvs.org/exploring-strategies-to-fill-gaps-in-medicaid-race-ethnicity-and-language-data/</a>



<sup>&</sup>lt;sup>27</sup> See Jared Bullard, *Improving Collection of Self-Reported Race & Ethnicity Data*, RTI HEALTH ADVANCE (Nov. 29, 2022), <a href="https://healthcare.rti.org/insights/improving-collection-of-self-reported-race-and-ethnicity-data">https://healthcare.rti.org/insights/improving-collection-of-self-reported-race-and-ethnicity-data</a>.

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, research finds that women of color report receiving poorer quality care than men of color, who report receiving poorer care than white men.<sup>29</sup> Spanish-speaking Latine individuals experience poorer quality care than English-speaking Latine individuals, who experience poorer care than non-Latine white individuals. 30 Compared to women without disabilities, women with disabilities are more likely not to receive regular mammograms or Pap tests.<sup>31</sup> People of color who have disabilities experience greater disparities in diagnoses and utilization of assistive technology.<sup>32</sup> While discrimination investigation sometimes focuses on variations based 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.

<sup>&</sup>lt;sup>32</sup> 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 in usage of assistive technology among people with disabilities, 20 Assist. Technol. 194-203 (2008).



<sup>&</sup>lt;sup>29</sup> 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).

<sup>&</sup>lt;sup>30</sup> 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).

<sup>&</sup>lt;sup>31</sup> 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).

- Conduct Regular Review of Data Collection Practices 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.<sup>33</sup> We support the use of focus groups, listening sessions, and direct outreach for testing of data collection methods on Form CMS-40B 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. We are encouraged by the adoption
  of CMS's new data resource website, <u>data.cms.gov</u>. For meaningful accountability, if
  CMS collects demographic information in its programs, it must make the resulting
  demographic data summaries and analysis available and accessible by the public and
  by researchers on <u>data.cms.gov</u> and elsewhere. Delays and barriers result in less
  accountability and less public ownership and agency over data.

#### IV. Conclusion

We appreciate the opportunity to provide comments on the Form CMS-40B. 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 <a href="mailto:gilfoil@healthlaw.org">gilfoil@healthlaw.org</a>.

<sup>&</sup>lt;sup>33</sup> 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), <a href="https://www.healthaffairs.org/doi/10.1377/hlthaff.2021.01417">https://www.healthaffairs.org/doi/10.1377/hlthaff.2021.01417</a>; 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), <a href="https://www.healthaffairs.org/do/10.1377/forefront.20210514.126700/">https://www.healthaffairs.org/do/10.1377/forefront.20210514.126700/</a>.



Sincerely,

Eli / Jag-

Elizabeth G. Taylor Executive Director

