March 14, 2021

Centers for Medicare & Medicaid Services
Department of Health and Human Services
7500 Security Boulevard
Baltimore, MD 21244

Submitted via https://www.regulations.gov

Re: CMS-10718, OMB 0938-1378, 86 Fed. Reg. 1752; Comments on Model Medicare Advantage and Medicare Prescription Drug Plan Individual Enrollment Request Form

Greetings:

Justice in Aging and SAGE appreciate the opportunity to comment on the above referenced notice. We are in strong support of the Centers for Medicare & Medicaid Services' (CMS's) commitment to advancing health equity pursuant to Executive Order 13985.[1] Efforts to increase and improve data collection at CMS will mitigate the gaps in demographic data, particularly around race and ethnicity, which in turn can inform efforts to pursue health equity.

Justice in Aging is an advocacy organization with the mission of improving the lives of low-income older adults nationwide. We use the power of the law to fight senior poverty by securing access to affordable health care, economic security, and the courts for older adults with limited resources, particularly populations that have been marginalized and excluded from justice such as people of color, people with disabilities, LGBTQ individuals, and people with limited English proficiency. We have decades of experience with Medicare and Medicaid and working with advocates who represent low-income older adults.

I. Race and Ethnicity Questions

We support CMS's efforts to increase response rates about and data collection of race and ethnicity. Lack of data across all fields continues to be a major impediment in understanding health inequities and implementing appropriate measures to tackle racial disparities. We believe the benefits of adding more accurate ethnic and racial categories to encourage enhanced self-identification far outweigh any risk of deterring responses.

We support the detailed checkboxes for Latino/a, Hispanic, and Spanish origin category in Section 2. Additionally, we support that Hispanic, Latino/a, and Spanish origin question is not called out as a separate category from race. A study conducted by the Census Bureau in 2010 found that this "combined" method yields higher response rates and allows individuals to self-identify more accurately.[2]

However, we urge CMS to analyze race and ethnicity data separately when conducting trend reports.

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[1] https://www.federalregister.gov/documents/2021/01/25/2021-01753/advancing-racial-equity-and-support-for-underserved-communities-through-the-federal-government

[2] https://www2.census.gov/programs-surveys/decennial/2020/program-management/final-analysis-reports/2015nct-race-ethnicity-analysis.pdf, page 7.

We suggest changing the question "What is your race?" to "What is your race/ethnicity?" Some individuals may not consider their ethnic origin as "race" or may be put off by characterizing it as such. We support the addition of detailed reporting for Asian American and Pacific Island (AAPI) and Native Hawaiian populations. This mirrors the 2015 National Content Test recommended format.

We strongly recommend adding a Middle Eastern and North African (MENA) category to this list. Data collection on MENA individuals across all federal agencies has been lacking for decades.[3]

Individuals with Middle Eastern, Arab, or North African heritage make up a significant percent of the U.S. population—anywhere between 1.6 to 5 million individuals.[4] Relatedly, 3% of the over 40 million immigrants in the U.S. immigrated from MENA countries.[5] Yet this sizeable population continues to be undercounted and misidentified across all federal agencies, including CMS. In light of the extensive discrimination that people of Middle Eastern origin have experienced in the United States, especially in recent decades, it is particularly important for equity reasons that CMS include the category in demographic data collection.

For these reasons, we urge CMS to add MENA to the enrollment form to bolster accurate data collection by *adding MENA as a separate category among the races.*

II. Sexual Orientation and Gender Identity Questions

Similarly, data collection is a vital tool to address discrimination and combat health inequities for LGBTQ individuals. The pursuit of health equity cannot overlook the importance of data collection on sex, sexual orientation and gender identity. Research shows LGBTQ individuals experience varying forms of disparities in health care, ranging from fear of discrimination to higher rates of poor physical health.[6] CMS is uniquely situated to affirm LGBTQ communities and standardize data collection in this area.

Questions about sexual orientation and gender identity (SOGI) should be asked alongside other demographic identifiers. Knowledge of an individual's SOGI status through an enrollment form will allow providers to provide better person-centered care—for example by understanding who the patient considers to be family, recommending routine exams, making appropriate referrals for social and behavioral health services, and enhancing training on services to specific populations.[7] CMS can use this collected data to analyze resultant data with various intersections of identities (e.g., enrollment trends of sexual orientation and race).

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[3] https://www2.census.gov/programs-surveys/decennial/2020/program-management/final-analysis-reports/2015nct-race-ethnicity-analysis.pdf, page 8.

[4] https://www.pewtrusts.org/en/research-and-analysis/blogs/stateline/2014/08/13/counting-americans-of-middle-eastern-north-african-descent

[5] https://www.immigrationresearch.org/report/migration-policy-institute/middle-eastern-and-north-african-immigrants-united-states

[6] https://www.sageusa.org/wp-content/uploads/2021/03/sage-lgbt-aging-facts-final.pdf, page 3

[7] https://www.lgbtagingcenter.org/resources/pdfs/Sage_CollDataGuidebook2016.pdf, page 6.

We recommend asking SOGI related questions into the general demographics section of forms—such as in Section 2 of the model enrollment form—as opposed to creating a separate section, which enforces feelings of stigma.[8]

We encourage CMS to engage with advocates and LGBT-identified individuals to solicit the terms and options they prefer when crafting and implement questions around SOGI on the enrollment form. SAGE USA has a useful resource on *Inclusive Questions for Older Adults: A Practical Guide to Collecting Data on Sexual Orientation and Gender Identity* which provides guidance creating SOGI questions. One recommendation from this resource, for example, is to add more inclusive options to the sex or gender questions that capture gender identity and transgender status. The form can also ask about both gender identity (with options that include transgender status and a "not listed above" option) in addition to a question about sex assigned at birth. Another recommendation is to simply ask "Do you think of yourself as: (a) Lesbian or gay; (b) Straight, that is, not gay or lesbian; (c) Bisexual; (d) Not listed above, please specify; or (e) Not sure."[9]

III. Language Questions

We support the question about language question by service area in Section 2, but suggest the following rewording: "We offer written information in ____ and ____. Please check if you want information in prefer information in _____ and _____.

While we understand CMS regulations require translations only for languages spoken by at least 5% of population served, there is a benefit to identifying primary languages on the enrollment form. This would allow the MA plans to identify individuals needing interpreter services when meeting with providers, through customer services phone lines, or at the pharmacy.

We also urge adding a broader language preference question: "When we speak with you, what language would you prefer: English Spanish Other (specify)_____."

Lastly, we renew previous requests for CMS to improve its current translation regulations. The current 5% threshold, which takes no account of the size of the population served, excludes large numbers of individuals with limited proficiency in English from meaningful access to information they need to use their plan benefits effectively. In almost all cases, speakers of languages other than English or Spanish get no benefit from the regulation.

IV. Conclusion

Thank you again for the opportunity to comment. If any questions arise concerning submission please contact Sahar Takshi at stakshi@justiceinaging.org.

Sincerely,

Justice in Aging
SAGE

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[8] https://www.lgbtagingcenter.org/resources/pdfs/Sage_CollDataGuidebook2016.pdf, page 11.
[9] https://www.lgbtagingcenter.org/resources/pdfs/Sage_CollDataGuidebook2016.pdf, page 12.