

# JUSTICE IN AGING

FIGHTING SENIOR POVERTY THROUGH LAW

September 12, 2025

Centers for Medicare & Medicaid Services (CMS),  
Office of Strategic Operations and Regulatory Affairs, Division of Regulations Development,  
Attention: Document Identifier/ CMS-P-0015A  
OMB Control Number: 0938-0568, Room C4-26-05,  
7500 Security Boulevard,  
Baltimore, Maryland 21244-1850.

Re: Form Number: CMS-P-0015A (OMB Control Number 0938-0568): Medicare Current Beneficiary Survey

**Submitted Electronically at** [www.regulations.gov](http://www.regulations.gov)

Justice in Aging writes to oppose the suggested and implemented changes to the Centers for Medicare & Medicaid Services' (CMS) proposal to reduce collection of information regarding activities of daily living, transportation, and communication and remove questions on gender identity and perceived discrimination from the Medicare Current Beneficiary Survey (MCBS).

Justice in Aging is a national legal advocacy organization with the mission of improving the lives of low-income older adults. We use the power of law to fight senior poverty by securing access to affordable healthcare, housing, and economic security for older adults with limited resources. We possess extensive expertise in federal programs that low-income older adults rely on, including Medicare. We focus on the needs of low-income communities who have traditionally lacked legal protections.

As CMS notes, the MCBS is the most comprehensive and complete survey available on the Medicare population and is essential in capturing information regarding Medicare not otherwise collected through operational or administrative data. Directed by the Office of Enterprise Data and Analytics (OEDA), the MCBS offers a comprehensive view of the social and medical risk factors of Medicare beneficiaries, their relationship to healthcare utilization, and health outcomes. The survey gives a complete picture of how Medicare works, shapes Medicare policies, and offers critical insight into the experiences of individuals enrolled in Medicare.

The proposed and approved changes undermine the comprehensive nature of the MCBS. Disrupting collection of important information hinders the effectiveness of Medicare program to combat discrimination in health care. The MCBS must continue to collect information about the needs of all communities and provide critical information for policymakers to craft evidence-based guidance and policies.

**Reducing collection of information related to instrumental activities of daily living (IADL) and activities of daily living (ADL) in the Health Status and Functioning Questionnaire (HFQ).**

Justice in Aging opposes CMS's proposal to remove and revise several dozen questions about people helping the Medicare enrollee with ADLs and IADLs. Significant gaps exist in our understanding of

*Washington, DC*



*Los Angeles, CA*



*Oakland, CA*

caregiving needs among Medicare enrollees, in large part due to a lack of reliable and comprehensive data. Removing so many questions from the MCBS may exacerbate those gaps and set us back in terms of understanding how to best support older adults and people with disabilities with long-term care needs and their caregivers.

In particular, we are concerned with removing the answers that identify in more detail who provides help with IADLs and ADLs and instead ask if the helper is a 1) Family member, 2) Friend, 3) Home health aide or home care worker, or 4) Homemaker or house cleaner. While we recognize that CMS may choose to categorize some of the answers in its analysis and reporting, we believe that the details are important for other researchers and to help inform effective policies. For example, when it comes to family members, whether people are relying on a spouse as opposed to a child or grandchild is important to how care is delivered and to designing programs and policies to support the full range of caregivers, as they include both adults and minors and people living with the Medicare enrollee and people living apart. Similarly, removing questions about how long a person has needed help and whether someone “stays nearby” while bathing, dressing, eating, transferring, walking, or toileting unnecessarily creates an information deficit. Caregiving takes many different forms, and someone may not realize that having someone nearby is a form of assistance unless they are asked. The length of time a person has needed help also provides insight into onset and progression of functional limitations and whether Medicare enrollees are seeking paid care to provide that assistance or relying on unpaid caregivers.

While there is likely room for improvement to this set of questions, we are concerned that removing many of them completely or revising the answer choices without adequate testing and more time for input from stakeholders who rely on this data will diminish the MCBS’s value and widen gaps in our knowledge of the caregiving needs of Medicare enrollees.

### **Removing items with low analytic utility from the Usual Source of Care Questionnaire (USQ).**

Justice in Aging opposes the proposal to remove 72 questions from the USQ related to travel time and distance from the respondent’s usual provider, whether they are accompanied to appointments and if so by whom, experiences with care from their usual provider, visits to specialists and hospitalizations, care coordination, and availability of test results.

We are particularly concerned with the proposal to remove five questions related to health care experiences and health care communication of enrollees with limited English proficiency (LEP). We believe the information solicited by these questions is important to understanding the language access needs of Medicare enrollees and, critically, whether and how providers are meeting those needs in compliance with federal laws like Title VI and Section 1557 of the Affordable Care Act. For example, the question, “who helps you communicate with your provider” yields data on whether Medicare enrollees with LEP are relying on family or other non-qualified interpreters instead of receiving professional interpretation and other language support from their providers.

The question “in what language do you prefer to receive your medical care” asks about language access needs in another way that may solicit helpful information that the question about how well you can communicate with your provider in English does not. For example, an individual may answer that they can communicate with their provider well in English but still prefer to receive information in a different language. Knowing these types of distinctions provides important information about what languages written materials should be translated into to meet the needs of Medicare enrollees.

CMS cites “low analytic utility” as the reason for removing these questions asked to respondents with LEP. On the contrary, **we recommend CMS take steps to improve the utility by making the survey more accessible to people with LEP.** The MCBS is only administered in English and Spanish. To increase participation by Medicare enrollees whose primary language is not English or Spanish, we recommend increasing the number of languages the survey is administered in to include the 15 most commonly spoken languages among Medicare enrollees.<sup>1</sup>

Recent research using MCBS data highlights the importance of improving access to the survey for LEP enrollees. The researchers assessed how LEP is associated with the use of Medicare resources and found that enrollees with LEP in reading were less likely to have used a CMS resource than enrollees who were non-LEP.<sup>2</sup> However, a noted limitation in the study is that MCBS is only administered in English and Spanish, and so there is limited representation people who do not speak either of those languages. CMS also cites decreasing survey respondent burden as a reason for removing these questions. However, we believe the existing skip logic already minimizes this burden. Instead of removing questions, we recommend using a more robust skip logic that ensures all respondents with LEP are able to report on their communication challenges and strategies with their providers.

We also oppose removing questions about transportation that ask how the Medicare enrollee usually gets to their provider’s office and, if driven or otherwise assisted, about the person who helps them. The answers to these questions provide important insight into how often Medicare enrollees are relying on caregivers in getting to the doctor. As discussed above in our comments about removal of questions related to help with daily activities, caregiving takes many forms and people who do not identify having a caregiver or help at home may still indicate that someone drives them to the doctor. In addition, the data about how a person gets to the doctor seems directly related to the question that will remain about how long it usually takes. For example, the implications of an hour or two of time getting to the doctor are different for a person using public transportation who needs to wait or transfer, than it is for someone who has to wait to get an accessible taxi. This is also different than someone who drives themselves but lives far away from their provider. From the perspective of understanding the heterogeneous Medicare population and their needs, the usefulness of the time data is diminished without also knowing the mode of transportation.

CMS does not specify the reason for removing these questions. However, if there are concerns about analytic utility, we recommend revising the questions rather than eliminating them completely.

### **Removing and changing questions about sexual orientation and gender identity (SOGI) and perceived discrimination.**

Justice in Aging opposes changes to the MCBS approved in April 2025 that removed questions and certain answers about SOGI and perceived discrimination beginning in Fall 2026. Here, we reiterate joint comments submitted by Movement Advancement Project, Justice in Aging, and others and write separately to detail our concerns.

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<sup>1</sup> See 42 CFR § 92.11, requiring covered entities to provide notice of availability of language assistance services in English and the 15 languages most commonly spoken by individuals with limited English proficiency of the state(s) where they operate. See also, CMS, [Understanding Communication and Language Needs of Medicare Beneficiaries](#) (2017).

<sup>2</sup> Estenson, et al., [Medicare Resource Use Differs by English Reading Proficiency](#), *Innovation in Aging*, Vol. 9, Issue 1 (2025).

The removal and changes to questions regarding sexual orientation and gender identity builds upon a vacuum of data collection for LGBTQ+ communities, including older adults, and will impede policymakers' efforts to address ongoing and persistent health inequities that LGBTQ+ Medicare enrollees and others experience.

There are approximately 18 million LGBT adults (aged 18 and older) in the United States, including 2.1 million transgender adults, of whom 154,800 are aged 65 and older.<sup>3</sup> Studies show surveys lack specific questions about sexual orientation, gender identity, and sex characteristics, so they fail to accurately account for LGBTQ+ communities.<sup>4</sup> When data is collected about LGBTQ+ individuals, there are issues with a lack of routine and consistent data.<sup>5</sup>

In light of this context, CMS removed questions about gender identity and options like “something else” for a question about sexual orientation and “assigned at birth” for a question about sex. Unfortunately, these changes are part of a long history of institutional discrimination against and neglect of LGBTQ+ older adults, particularly in health care. Without SOGI data, CMS cannot craft policies to address ongoing inequities that LGBTQ+ Medicare enrollees face.<sup>6</sup> Furthermore, discontinuing the questions hinders the goal of adaptability and consistency.

In addition, we oppose to remove the question about perceived discrimination, which asks about perceived discrimination from health care providers due to certain personal attributes, like race or ethnicity, language or accent, gender or gender identity, sexual orientation, age, culture or religion, disability or medical history. The wholesale removal of this question stymies efforts to understand discrimination against Medicare enrollees in the provision of health care on multiple bases, many of which are protected characteristics, and enforce their civil rights to be free from discrimination in the Medicare program. Removing this question runs counter to even CMS's own Supporting Statement Part A from earlier this year, which indicated that the MCBS is “an important tool for assessing health disparities among Medicare beneficiaries,” and discusses how additional efforts in collaboration with the Office of Minority Health (OMH) improved response rates for Hispanic, Black, and Asian enrollees in the past.<sup>7</sup>

CMS has indicated that the removal of this question will increase efficiency by saving surveyants 0.7 minutes, but the cost is far greater. While individuals may have one less question to read through and answer, the costs of discrimination in health care are significant and well-documented. A growing body of research confirms the extent to which older adults are discriminated against in health care. For example, in the U.S. one in four Black and Latinx/Hispanic adults age 60 and older report that they have been treated unfairly or have felt that their health concerns were not taken seriously by health

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<sup>3</sup> See [Brief of Amici Curiae of Williams Institute Scholars in support of Respondents 7](#), *Chiles v. Salazar*, No. 24-539 (U.S. 2025).

<sup>4</sup> Caroline Medina and Lindsay Mahowald, [Collecting Data About LGBTQI+ and Other Sexual and Gender-Diverse Communities](#), Center of American Progress, The Center for American Progress (May 24, 2022).

<sup>5</sup> *Id.*

<sup>6</sup> Heather Schoonover, [Many Health Systems Are Failing the LGBTQ+ Community—Two Ways to Improve](#), Health Catalyst.

<sup>7</sup> Office of Enterprise Data and Analytics, [Supporting Statement A for Revision of Currently Approved Collection: Medicare Current Beneficiary Survey](#), Centers for Medicare and Medicaid Services (March 10, 2025).

professionals because of their racial or ethnic background. More than a quarter of U.S. older adults said they did not get the care or treatment they felt they needed because of discrimination.<sup>8</sup>

Information from the 2023 MCBS supports these findings. Medicare enrollees under 65 years, people speaking a language other than English at home, enrollees with race/ethnicity other than White non-Hispanic, Black non-Hispanic, Hispanic, or Asian, and enrollees who identify as lesbian, gay, or bisexual were more likely to report being treated in an unfair or insensitive way by a healthcare provider.<sup>9</sup> Meanwhile, ageism in healthcare, like misattributing pain and other symptoms as a natural part of aging, speaking down to older patients (called "elder speak"), and over-compensating with unnecessary medication, sometimes known as overmedicalization, costs the U.S. upwards of \$63 billion annually.<sup>10</sup> Additional research highlights the link between perceived discrimination and participation in unhealthy and nonparticipation in healthy behaviors and negative health outcomes.<sup>11</sup> Ignoring perceived discrimination does nothing to address the discrimination Medicare enrollees face; in fact, asking about it is a crucial first step toward understanding and combating that discrimination.

## Conclusion

The MCBS provides key insights into the experiences of Medicare enrollees to CMS and others. Removing and otherwise changing questions related to activities of daily living, communication, transportation, gender identity and perceived discrimination compromises the ability of CMS to effectively serve all Medicare enrollees, erodes the foundation for evidence-based policymaking, and call into question CMS's commitment to transparency, scientific integrity, and the equitable treatment of all individuals enrolled in the Medicare program.

Thank you for the opportunity to comment on the proposed and implemented changes to the MCBS. If any questions arise concerning this submission, please contact Natalie Kean at [nkean@justiceinaging.org](mailto:nkean@justiceinaging.org) and Archie Roundtree Jr. at [aroundtree@justiceinaging.org](mailto:aroundtree@justiceinaging.org).

Sincerely,



Denny Chan  
Managing Director, Equity Advocacy

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<sup>8</sup> Michelle M. Doty, et. al, [How Discrimination in Health Care Affects Older Americans, and What Health Systems and Providers Can Do](#), The Commonwealth Fund (April 21, 2022).

<sup>9</sup> CMS Data Briefs and Tutorials, [2023 Perceived Discrimination by Healthcare Provider Infographic](#), Centers for Medicare & Medicaid Services (2024).

<sup>10</sup> Andrew Steward, [Age Discrimination in Healthcare: The Argument for a Multi-Level Intersectional Response](#) 4 CSA Journal. 49 (2023); Regis College, [Why Ageism in Health Care is a Growing Concern](#), Regis College (Oct. 28, 2021).

<sup>11</sup> Elizabeth A Pascoe & Laura Smart Richman, [Perceived Discrimination and Health: A Meta-Analytic Review](#), Psychol Bull. (2009).