

September 12, 2025

William N. Parham, III

Director, Division of Information Collections and Regulatory Impacts

Office of Strategic Operations and Regulatory Affairs

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

The undersigned organizations submit this comment to express serious concern regarding the Centers for Medicare & Medicaid Services' (CMS) decision to remove demographic questions on gender identity and to eliminate the measure of perceived discrimination by health care providers due to personal characteristics from the Medicare Current Beneficiary Survey (MCBS).

The MCBS is the only nationally representative survey of Medicare beneficiaries that provides a holistic view of beneficiaries' social and medical risk factors and how these intersect with health care utilization, costs, and outcomes. Data from MCBS are used to estimate total Medicare health care costs and utilization, as well as to develop and monitor programs and initiatives intended for Medicare beneficiaries. CMS is now revising this important survey to revise the sexual orientation question to remove the "something else" option, remove the gender identity questions, and remove the question on perceived discrimination by health care providers due to personal attributes, including race or ethnicity, language or accent, gender or gender identity, sexual orientation, age, culture or religion, disability, or medical history.

The changes proposed by CMS will undermine its ability to effectively administer the Medicare program, fulfill statutory obligations, support the enforcement of civil rights laws, and inform evidence-based policymaking.

1. Statutory obligations require the collection of comprehensive demographic data and information on experiences of discrimination

Since the creation of Medicare through the Social Security Amendments of 1965, Congress has obligated the Secretary of the U.S. Department of Health and Human Services to evaluate approaches for the collection of data for the Medicare program to "allow for the ongoing, accurate, and timely collection and evaluation of data on disparities in health care services and performance on the basis of race, ethnicity, and gender."¹ Multiple resources indicate that CMS administers various data collections, including MCBS, to effectuate this mandate.² As CMS

¹ 42 U.S.C. § 1395b-10(a).

² See, e.g., SORN 09-70-0500, HHS.GOV, <https://www.hhs.gov/foia/privacy/sorns/09700500/index.html> (last accessed Sept. 3, 2025) (noting that CMS's authority to maintain the Health Plan Management System, which

itself has noted, the MCBS data are especially important because the survey provides information on Medicare beneficiaries that is not available in CMS administrative data.³

The proposed changes, including eliminating demographic questions on gender identity and perceived discrimination, also conflict with CMS' responsibilities under the Evidence-Based Policymaking Act of 2018 and the Paperwork Reduction Act, which emphasize the federal government's obligation to gather and evaluate high-quality data to inform program administration and policy development. Through the MCBS, CMS must demonstrate scientific integrity and methodological rigor by providing objective, accurate, and timely information about the experiences of beneficiaries. Removing these questions strips away a critical source of information about barriers faced by beneficiaries, weakens the ability to identify disparities in access, treatment, and outcomes, and design solutions to address those issues.

In addition, CMS' proposal to eliminate the perceived discrimination question will also hinder monitoring and enforcement of federal nondiscrimination protections. For example, Title VI of the Civil Rights Act, Section 1557 of the Affordable Care Act, Section 504 of the Rehabilitation Act, and the Age Discrimination Act prohibit discrimination in federally funded programs such as Medicare. Without reliable data on whether beneficiaries experience discrimination based on characteristics such as race, language, gender identity, sexual orientation, disability, and/or age, CMS cannot effectively assess compliance with these statutes. The absence of such data would not only impede civil rights enforcement but also limit CMS's ability to proactively identify patterns and take corrective action to ensure all beneficiaries receive equitable care.

2. LGBTQ+ older adults, especially transgender adults, face health disparities and rely on Medicare

Research consistently demonstrates that LGBTQ+ older adults experience significant disparities in health, disability, and economic security compared to their non-LGBTQ+ peers.⁴ According to the Williams Institute, 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 transgender adults aged 65 and older.⁵ The population of LGBT older adults in the United States is projected

"collect[s] and maintain[s] information on Medicare beneficiaries enrolled in Medicare Health Plans," is granted by 42 U.S.C. § 1395ll); About the MCBS, NORC AT THE UNIVERSITY OF CHICAGO <https://mcbs-interactives.norc.uchicago.edu/about/mcbs/> (last accessed Sept. 3, 2025).

³ Medicare Current Beneficiary Survey (MCBS), DATA.CMS.GOV, <https://www.cms.gov/data-research/research/medicare-current-beneficiary-survey> (last accessed Sept. 3, 2025).

⁴ National Academies of Sciences, Engineering, and Medicine. 2020. *Understanding the Well-Being of LGBTQI+ Populations*. Washington, DC: The National Academies Press. <https://doi.org/10.17226/25877>.

⁵ See Brief of Amici Curiae of Williams Institute Scholars in support of Respondents 7, *Chiles v. Salazar*, No. 24-539 (U.S. 2025), https://www.supremecourt.gov/DocketPDF/24/24-539/370799/20250826162449953_24-539%20Amicus%20Brief.pdf.

to steadily increase with some studies predicting that by 2030 there will be 7 million LGBTQ+ Americans over the age of 50.⁶

Transgender adults in particular experience higher rates of disability and chronic conditions, coupled with economic barriers such as unemployment and poverty, making them more likely than cisgender adults to rely on Medicare, often through disability-based eligibility before age 65.⁷ Because CMS has not consistently included questions related to sexual orientation and gender identity on its information collections, research specifically on LGBTQ+ Medicare beneficiaries remains limited. The removal of gender identity questions from MCBS eliminates yet another critical source for these data.

Inclusion of sexual orientation and gender identity items in federal surveys such as the MCBS should follow best practices for measurement, such as those recommended by the National Academies of Sciences, Engineering, and Medicine.⁸ Retaining these voluntary questions is essential to build a more accurate understanding of the needs of LGBTQ+ beneficiaries. At the same time, CMS must ensure that all demographic information, including sexual orientation and gender identity data collected through federal surveys including the MCBS, are gathered, analyzed, and reported in compliance with the strongest applicable privacy and confidentiality standards. Protecting respondents' information is critical to building trust and should be achieved by meeting the requirements of robust safeguards.

3. Data about perceived discrimination by health care providers are essential to ensure accountability

Evidence shows that discrimination in health care is both widespread and harmful, yet data on the experiences of Medicare beneficiaries specifically is limited. According to a 2023 study by KFF, about one in five (18%) Black adults and roughly one in ten American Indian and Alaska Native (12%), Hispanic (11%), and Asian (10%) adults who received health care in the past three years report being treated unfairly or with disrespect by a health care provider because of their racial or ethnic background.⁹ Additionally, a 2024 study by the Center for American Progress

⁶ SAGE, *The Facts on LGBT Aging* (July 2025), <https://www.sageusa.org/wp-content/uploads/2025/08/sageusa-the-facts-on-lgbt-aging.pdf> (last visited Sept. 3, 2025).

⁷ See Ana M. Progovac et al., *Identifying Gender Minority Patients' Health and Health Care Needs in Administrative Claims Data*, 37 Health Affs. (Millwood) 413 (2018), <https://doi.org/10.1377/hlthaff.2017.1295>; C.N. Dragon et al., *Transgender Medicare Beneficiaries and Chronic Conditions: Exploring Fee-for-Service Claims Data*, 4 LGBT Health 404 (Dec. 2017) (PMCID: PMC5731542).

⁸ National Academies of Sciences, Engineering, and Medicine. 2022. *Measuring Sex, Gender Identity, and Sexual Orientation*. Washington, DC: The National Academies Press. <https://doi.org/10.17226/26424>.

⁹ KFF, *LGBT Adults' Experiences With Discrimination and Health Care Disparities: Findings From the KFF Survey of Racism, Discrimination, and Health*, KFF.org (May 2024), <https://www.kff.org/racial-equity-and-health-policy/lgbt-adults-experiences-with-discrimination-and-health-care-disparities-findings-from-the-kff-survey-of-racism-discrimination-and-health/#4344a9b1-0a44-42ed-b35a-0aed524a5e80> (last visited Sept. 3, 2025)

found that more than one-third of transgender adults (37 percent) postponed or did not try to access needed medical care due to the fear of experiencing disrespect and discrimination.¹⁰ Negative experiences and discrimination by health care providers contribute to worse health outcomes, delays in care, and diminished trust in the healthcare system.¹¹

The MCBS is the only nationally representative survey of Medicare beneficiaries that captures perceived discrimination by health care providers, filling a critical data gap on the experiences of older adults and people with disabilities left by other federal data collections. For example, inclusion of a question about perceived discrimination by health care providers in the 2024 MCBS provides evidence that beneficiaries under 65 years; people speaking a language other than English at home; beneficiaries with race/ethnicity other than White non-Hispanic, Black non-Hispanic, Hispanic, or Asian; and beneficiaries who identify as lesbian, gay, or bisexual were more likely to report being treated in an unfair or insensitive way by a healthcare provider.¹² Eliminating the perceived discrimination question would erase one of the few tools available for CMS to monitor discrimination in Medicare, while also depriving researchers, policymakers, and advocates of critical data needed to identify barriers to care, develop solutions, and hold the health care system accountable.

4. Request for action

In light of the evidence of the necessity of questions on gender identity and perceived discrimination, the undersigned respectfully request that CMS act immediately to:

1. **Reinstate voluntary demographic data questions about gender identity** as previously included on the MCBS.
2. **Reinstate the MCBS question about perceived discrimination** due to certain personal attributes, including race or ethnicity, language or accent, gender or gender identity, sexual orientation, age, culture or religion, disability, or medical history.
3. **Publicly disclose the rationale for removing these questions**, including any internal review or justification, to restore trust in the agency's commitment to unbiased, scientifically valid data collection.

Conclusion

Removing demographic questions on gender identity and the measure of perceived discrimination from the MCBS will eliminate a critical tool for identifying disparities in access,

¹⁰ <https://www.americanprogress.org/article/the-lgbtqi-community-reported-high-rates-of-discrimination-in-2024/>

¹¹ National Academies of Sciences, Engineering, and Medicine. 2020. *Understanding the Well-Being of LGBTQI+ Populations*. Washington, DC: The National Academies Press. <https://doi.org/10.17226/25877>.

¹² Centers for Medicare & Medicaid Services, *2023 Perceived Discrimination by Healthcare Provider Infographic*, Medicare Current Beneficiary Survey (July 2024), <https://www.cms.gov/data-research/research/medicare-current-beneficiary-survey/data-briefs-tutorials/2023-perceive-d-discrimination-healthcare-provider-infographic>.

treatment, and outcomes. It would also impede enforcement of civil rights protections and weaken the evidence base needed to design programs that meet beneficiaries' needs. CMS has a statutory responsibility to collect unbiased, scientifically valid data that reflect the realities of all Medicare beneficiaries. Abandoning these questions in response to politically motivated directives would compromise that responsibility, erode the foundation for evidence-based policymaking, and undermine trust in CMS's commitment to transparency and scientific integrity.

Thank you for your consideration of this important matter.

Abortion Forward

All* Above All

Arkansas Black Gay Men's Forum

Autistic Self Advocacy Network (ASAN)

Autistic Women & Nonbinary Network

Autistic Women & Nonbinary Network

CenterLink

Disability Rights Education and Defense Fund (DREDF)

Equality California

GLMA: Health Professionals Advancing LGBTQ+ Equality

Justice in Aging

League of United Latin American Citizens (LULAC)

Movement Advancement Project

National Action Network

National Health Law Program

National LGBTQ Task Force Action Fund

National Partnership for Women & Families

National Women's Law Center

Oasis Legal Services

Rocky Mountain Equality

Rural Organizing

SAGE

Silver State Equality

The Institute for Health Research & Policy at Whitman-Walker

Transgender Law Center

Transhealth

TransLatin@ Coalition

U.S. Gender and Disability Justice Alliance