

# Race and Ethnicity Data Collection Practices and Challenges on the Medicare Part C and Part D Enrollment Form

Authors: Morgan Murray (NORC), Susan Cahn (NORC), Nancy Chiles Shaffer (CMS OMH), Wen Song (CMS OMH), Meagan Khau (CMS OMH), and AnhViet Nguyen (CM)

## Introduction

One important way that the Centers for Medicare & Medicaid Services (CMS) is working to address health and care inequities is through stratified reporting of quality measures. The ability to analyze disparities across Medicare programs and policies depends on the collection and use of reliable, granular **self-reported** race and ethnicity data.<sup>1</sup>

- May 2022 – CMS requested Office of Management and Budget (OMB) approval to add optional questions on race and ethnicity to enrollment forms for Medicare Advantage health plans (MA) and Medicare Prescription Drug Plans (PDP) (Medicare Parts C and D, respectively).
- July 2022 – OMB approved adding optional race and ethnicity questions to the enrollment forms.
- January 2023 – Optional race and ethnicity questions are required to be used for Part C and Part D enrollment requests.

OMB also requested that CMS study possible reasons for non-response to the race and ethnicity questions among non-responders.<sup>1</sup> CMS OMH and NORC reviewed the demographic characteristics of responders vs. non-responders. This poster presents the demographic characteristics and findings from the study.

## Methods

The team selected a purposive sample of enrollees who did not respond to the optional race and ethnicity questions when enrolling during the Medicare Advantage Open Enrollment Period (MA OEP) and Annual Enrollment Period (AEP). Telephone interviews were conducted in English and Spanish in April – July 2023 and January – February 2024. Researchers coded and analyzed interview transcripts and notes to identify themes related to drivers of non-response and perceptions of the questions and response options.

A subsequent analysis was completed to compare the demographic and enrollment characteristics of the non-responders and responders during the MA OEP and AEP (N=7,326,742). In addition, an analysis of the self-reported race (N=3,028,576) and ethnicity (N=2,795,210) data of responders was also completed.<sup>2</sup>

### Key Findings about Nonresponse to the Optional Race and Ethnicity Questions

- At the time of both phases of the study most participants (65%) did not remember seeing the enrollment form or questions.
- The majority of participants who did not recall the form stated that they would have answered both questions if they had seen them.
- Over half of participants did not have any concerns with answering questions about race or ethnicity.
- Approximately 25% of participants had difficulty following the race and ethnicity questions when they were read aloud during the interview.
- This study could not verify whether participants intentionally skipped the optional questions or did not see the form or questions.

### Attitudes towards CMS Collection of Race and Ethnicity Data

- The majority (>75%) of study participants thought that CMS should collect data on race and ethnicity.
- Several participants acknowledged that certain races and ethnicities have a higher risk of specific health conditions and / or outcomes so CMS should collect these data to provide improved care.
- Some participants did not believe CMS should collect race and ethnicity data expressed concerns about the relevancy of the information for Medicare, tracking or political motivation, and potential discrimination.
- However, concerns about privacy and confidentiality were not frequently mentioned among respondents.

Demographic	Non-Responders (N = 3,018,910)	Responders (N = 4,307,832)
<b>Age Group</b>	<b>N (%)</b>	
<65 years	401,242 (13.3%)	546,333 (12.7%)
65-84 years	2,432,301 (80.6%)	3,505,108 (81.4%)
85+ years	185,367 (6.1%)	256,391 (6.0%)
<b>Sex</b>		
Male	1,317,037 (43.6%)	1,888,451 (43.8%)
Female	1,701,873 (56.4%)	2,419,381 (56.2%)

“Good question, I think medically, we’re finding out more and more that there are medical issues that are more prevalent in certain groups, and so, having the system aware of how many people are in those groups so that they’re prepared to meet their medical needs, I suppose it could be helpful...there are medical issues or health issues that are more prevalent or particular to certain races and ethnicities. I suppose that would be helpful information. I think it should be included.”  
- Cognitive interviewee in support of data collection

“We’re placing people in boxes, labeling them. If we’re all supposed to be equal, why? Why are we putting boxes, fences around us? ... It shouldn’t be that way. It shouldn’t make a difference whether they’re African, Samoan, Asian—anything. If you’re an American, you’re American. That’s all it should be.”  
- Cognitive interviewee opposed to data collection

Characteristic	Non-Responders	Responders
<b>Plan Type</b>		
MA-Only	99,784 (3.3%)	101,029 (2.3%)
MA-PD	2,107,214 (69.8%)	3,074,647 (71.4%)
PDP Only	811,912 (26.9%)	1,132,156 (30.7%)

### Responders Self-Reported Ethnicity during Annual Enrollment Period



### Responders Self-Reported Race during Annual Enrollment Period



### Demographic Breakdown

- The majority of responders to the optional ethnicity question self-identified as non-Hispanic (88%).
- The majority of responders to the optional race question self-identified as white (83%), followed by Black/African American (12%).
- There were no notable differences between non-responders and responders broken down by age group, sex, plan type, or CMS region (data not shown).

### Key Takeaways

- Self-reported race and ethnicity data is important and useful for CMS to collect, and the majority of respondents do not have any issues or concerns with these data being collected. These data will help CMS address disparities and improve health equity moving forward.
- There are no major differences between non-responders and responders across age category, sex, region, or plan type.
- Several participants showed confusion between the differences of race, ethnicity, nationality, and religion during the interview when asked about their attitudes towards race and ethnicity questions and the response options.
- Additional information about the purposes of the questions and instructions on the enrollment form may encourage self-reporting and may minimize confusion.

<sup>1</sup> Under contract with CMS, NORC at the University of Chicago conducted the cognitive interview study.

<sup>2</sup> Demographic, enrollment, and self-reported data were pulled from different Medicare beneficiary data sets, resulting in different sample sizes.

