

May 31, 2024

The Honorable Chiquita Brooks-LaSure
Administrator
Centers for Medicare & Medicaid Services
Submitted via regulations.gov

RE: CAHPS Hospice Survey, revision of a currently approved collection, CMS-10537 (OMB control number: 0938-1257)

We appreciate the opportunity to comment on the Collection of Information notice for the Consumer Assessment of Healthcare Providers and Systems (CAHPS) Hospice Survey.

Press Ganey is the leading provider of patient and member experience measurement, performance analytics and strategic advisory solutions for health plans and health care organizations across the continuum of care. For more than 30 years, our mission has been to help health care organizations reduce patient suffering and improve clinical quality, safety, workforce and caregiver engagement, and the patient experience. As of January 1, 2024, we serve more than 41,000 health care facilities.

Addition of a question regarding unfair treatment

The Attachment A, "Revised CAHPS Hospice Survey," indicates a question will be added regarding perception of unfair treatment, specifically: "How often was your family member treated unfairly by the hospice team because of their race or ethnicity?" (answer options: Never, Sometimes, Usually, Always)

We strongly support the addition of questions aimed at identifying and quantifying experiences of unfair or insensitive treatment. However, we have concerns regarding the proposed wording of the new question and its potential implications. We believe that modifications are necessary to ensure that the question accurately captures the intended data without leading or biasing responses.

The frequency-based format of this question may inadvertently suggest an assumption that such treatment did occur. This wording could influence how respondents interpret and answer the question, potentially leading to biased or skewed responses. It is crucial that survey questions remain neutral and do not imply an expectation of negative experiences.

To better align with best practices in survey design and to capture a more comprehensive range of factors that could influence perceptions of care, we suggest revising the question to be more inclusive and less assumptive.

This approach is being successfully implemented in other CAHPS programs (e.g., Medicare Advantage and Prescription Drug Plan CAHPS Survey) and could be adapted for the Hospice CAHPS Survey as follows: "Was your family member ever treated in an unfair or insensitive way because of any of the following things about them? Mark one or more."

- Health condition
- Disability
- Age
- Culture or religion
- Language or accent
- Race or ethnicity
- Sex (female or male)
- Sexual orientation
- Gender or gender identity
- Income
- I was not treated in an unfair or insensitive way

This alternative wording not only avoids presupposing that unfair treatment occurred but also broadens the scope to include various dimensions of potential bias, thus providing a more accurate measure of the patient and family experience. This format encourages respondents to think about a range of possible reasons for feeling treated unfairly, which is crucial for identifying specific areas where hospice care can improve.

Collecting nuanced data about experiences of unfair or insensitive treatment is critical for understanding and addressing disparities in end-of-life care. By expanding the range of reasons for potential discrimination or insensitivity, CMS can gain deeper insights into the prevalence and nature of these issues, which is essential for fostering improvements in care quality and equity.

Comments on additional proposed changes

The Collection of Information notice also highlights several other changes proposed by CMS in the Medicare Hospice Wage Index and Payment Rate Update for Fiscal Year (FY) 2025. Below are our comments on these proposed changes to the CAHPS Hospice Survey.

We acknowledge and support many of the proposed modifications aimed at refining the CAHPS Hospice Survey, improving data collection, and enhancing patient care through a more streamlined and considerate survey format.

Survey question wording and structure

We support the simplification and modernization of language in the CAHPS Hospice Survey, such as removing redundant phrases (e.g., "while your family member was in hospice care") and adopting gender-neutral pronouns, which align with broader trends in survey design across various programs and platforms. Likewise, we support

consolidating the "Getting Hospice Care Training" questions into a singular, comprehensive question to provide further simplification.

These changes not only make the survey more inclusive but also enhance readability and reduce respondent burden, which are critical factors in improving response rates and the reliability of data collected.

Addition of Care Preferences questions

The inclusion of two new items focused on Care Preferences is a positive step towards measuring patient-centered quality of care. This initiative aligns with patient-centered care models that are increasingly being adopted in healthcare systems more broadly. By asking directly about care preferences, CMS can gather actionable insights into how well hospice services are meeting individual needs and aligning to the preferences of patients and their families, thereby driving improvements in care delivery.

Introduction of a web-first mode

The addition of a web-first mode for the CAHPS Hospice Survey, following its implementation in other CAHPS surveys such as OAS CAHPS and HCAHPS, brings both opportunities and challenges. The web-first approach aligns with modern survey techniques, potentially increasing efficiency and reducing costs associated with paper and mail processes. It could better address respondent preference and can provide faster data turnaround for analysis.

However, the appropriateness of a web-first mode in the context of hospice care warrants careful consideration. The sensitive nature of hospice services and end-of-life care, means that recipients of the survey are often in a state of grief and loss. The impersonal nature of electronic communications might not resonate well with all bereaved families, potentially affecting their willingness to engage with the survey.

Despite these concerns, if CMS testing of the web-mail mode has demonstrated that this method does not negatively impact response rates or the quality of the data collected, it could be seen as a viable option. Nevertheless, it remains essential to ensure that these findings are robust and that the web-first mode truly meets the needs of all stakeholders, particularly the families and caregivers who are in the process of grieving.

Additionally, in our experience with surveys sent via email or text messages in non-regulatory programs, we have observed that while digital methods can reach a broader audience, the timing of such communications is crucial. In the context of hospice care, it is important to consider when and how these communications are sent, to be respectful and considerate of the emotional state of the survey recipients.

Addition of a pre-notification letter

The proposal to introduce a pre-notification letter to the CAHPS Hospice Survey process has advantages and potential drawbacks. Sending a pre-notification letter is widely recognized as a best practice in survey methodology. Research consistently shows that

such pre-notifications can enhance response rates by alerting respondents to the upcoming request for their participation, thereby increasing their preparedness and likelihood to respond.

However, while the benefits are clear, the financial implications for hospices are a concern that warrants acknowledgement. Introducing a pre-notification letter incurs additional costs for printing, handling, and mailing, which may not be negligible, especially for hospices operating under tight budget constraints. These costs could affect not only the direct financial outlay but also administrative burden, as staff or resources might need to be reallocated to manage this additional step in the survey process.

Given these considerations, the burden estimated associated with the CAHPS Hospice Survey may need to be updated to reflect these potential new costs. This would help ensure that all stakeholders, particularly hospice providers, fully understand the financial implications and can plan accordingly.

Inclusion of updated race and ethnicity data collection standards

In late March, the Office of Management and Budget (OMB) published a set of revisions to Statistical Policy Directive No. 15 (SPD 15): “Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity.”¹ SPD 15 provides guidance to federal agencies regarding collecting race and ethnicity information.

The revised guidance includes key updates such as combining race and ethnicity questions into a single question and adding a Middle Eastern or North African (MENA) category. To facilitate implementation, the guidance offers three illustrative examples of question formats that comply with SPD 15: (1) race and ethnicity question with multiple detailed checkboxes, and write-in response areas; (2) race and ethnicity question with minimum categories only and examples; and (3) race and ethnicity question with minimum categories only.

These changes offer opportunities to enhance the accuracy of health disparities research and ensure that policy decisions are informed by data that more accurately reflects the diversity of the U.S. population. We recommend expedited inclusion of these new categories in the CAHPS Hospice Survey to improve our understanding and address disparities.

In the context of the CAHPS Hospice Survey, which aims to understand patient and family experience with hospice care, clarity and inclusiveness are paramount. The format including examples (option 2) could be particularly effective, as it helps ensure that respondents accurately select the category that best represents them. However, the introduction of more detailed categories adds length and complexity to the survey. If the CAHPS Hospice Survey faces challenges with response rates or respondent burden, the

¹ Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity, 89 FR 22182 (28 March 2024) (pg. 22182-22196) <https://www.federalregister.gov/d/2024-06469>

simpler format (option 3) may be more appropriate. It provides essential categories for classification without potentially overwhelming respondents.

Furthermore, to ensure clarity and fairness in response options, all categories should be listed alphabetically. This approach not only aids in eliminating any potential bias in the ordering of options but also enhances the ease of navigation for respondents, leading to more accurate responses.

We support the swift implementation of OMB's revised standards for the collection of race and ethnicity data. It is crucial that the CAHPS programs incorporate these updates promptly to better understand and address disparities effectively across diverse populations.

We value the efforts by CMS to improve the CAHPS Hospice Survey and the data collection process. We appreciate the opportunity to provide feedback and look forward to supporting continued refinement of the survey to better serve the needs of hospice patients and their families.

For further information on our comments and recommendations, please contact:

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