



May 30, 2023

The Honorable Chiquita Brooks-LaSure  
Administrator  
Centers for Medicare & Medicaid Services  
Department of Health and Human Services  
Hubert H. Humphrey Building  
200 Independence Avenue, S.W.  
Washington, DC 20201

Submitted electronically to <http://www.regulations.gov>

Re: CMS-1787-P. Medicare Program; FY 2024 Hospice Wage Index and Payment Rate Update, Hospice Conditions of Participation Updates, Hospice Quality Reporting Program Requirements, and Hospice Certifying Physician Provider Enrollment Requirements.

Dear Administrator Brooks-LaSure:

AARP, which advocates for the more than 100 million Americans age 50 and older, appreciates the opportunity to comment on this Fiscal Year 2024 Medicare hospice payment proposed rule. Our comments on this proposed rule, from the perspective of Medicare beneficiaries and their family caregivers, will focus on two requests for information and provisions regarding family caregivers.

RFI on Hospice Utilization; Non-Hospice Spending; Ownership Transparency; and Hospice Election Decision-Making

AARP shares CMS' concerns that although hospice use has grown considerably since the 1983 inception of the Medicare benefit, there are still barriers that terminally ill and benefit eligible beneficiaries may face when trying to access hospice care. We are particularly concerned that beneficiary populations with complex palliative needs and potentially high-cost medical care needs may underuse the hospice benefit. We believe the reasons for this may be complex, including lack of transparency of what the hospice benefit covers and what Medicare covers for conditions unrelated to the terminal illness. Other factors may also contribute, such as the continued growth in for-profit entities that may support patients with longer lengths of stay. We urge CMS to conduct further analysis and study on these serious trends and issues to help improve quality of care and access to hospice services as well as health equity.

In the proposed rule, CMS requested comment on more than a dozen questions related to hospice utilization, non-hospice spending, owner transparency and hospice election decision making. We identified solutions that could help address many of these issues identified in CMS' questions

and thus our responses are thematic rather than specific answers to each question posed in the RFI. Specifically, our comments focus on the following areas: (1) patient notification of hospice non-covered items, services, and drugs; (2) non-hospice spending during a hospice election; (3) hospice ownership status; and (4) information to support family caregivers.

#### *Patient Notification of Hospice Non-Covered Items, Services, and Drugs*

AARP believes that beneficiaries should be fully informed of their rights and benefits before and after electing hospice care under the Medicare benefit relative to what services are covered under Medicare hospice and the patients' rights and payment responsibilities. As we emphasized in our response to the FY 2020 Medicare hospice proposed rule, AARP continues to believe that all beneficiaries and their representatives should automatically receive the election statement addendum within 2 days after the time of election and any updates to the election should also be automatically provided within 2 days. If appropriate, such information should also be shared with the beneficiary's family. To increase transparency, AARP believes that the provision of the election statement addendum should be a requirement, and not just upon request by the beneficiary (or representative). The current regulations at §418.24 (d)(1) specify that the hospice election addendum is only available upon request and then must be provided within 5 days of the request if requested within the first 5 days of hospice election or within 3 days if requested after the first 5 days of the hospice election. Requiring the hospice election statement to be automatically provided to all beneficiaries and their families (as appropriate) would be consistent with CMS' goals to provide greater transparency about coverage under the hospice benefit and inform the beneficiary about services that might need to be obtained outside the hospice benefit.

Specifically, we suggest that CMS revisit the Medicare hospice regulations at §418.24 (d)(1) and that they be modified to state the following: "The hospice must provide the addendum, in writing, to the individual (or representative), non-hospice-provider, or Medicare contractor within 2 days of a hospice election. If the individual consents, the addendum should be shared with the individual's family caregiver(s)." It should be clear the addendum must be provided to the beneficiary (or representative) and the other entities noted, as appropriate. The regulation at §418.24 (d)(2) and (d)(3) would need to be modified to specify that any future requests or any changes to the addendum would also need to be provided within 2 days.

AARP also supports medication therapy management (MTM) programs that help minimize preventable medication-related problems and encourage appropriate prescribing, monitoring, and safe use of medications. We believe that beneficiaries who have elected hospice care could benefit from MTM to ensure their medication regimen is appropriate. We recommend that CMS consider adding hospice as an eligible criterion for MTM programs<sup>1</sup> and this information also be included on the Part D sponsor MTM program website.

CMS has noted an increase in hospice beneficiaries filling prescriptions for maintenance drugs. This new benefit could also address the increase in hospice beneficiaries filling prescriptions for maintenance drugs, as it would create an opportunity for providers to highlight medications that the beneficiary may wish to discontinue and/or ensure they are aware of any financial

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<sup>1</sup>§423.153(d)

implications should they wish to continue taking them. CMS should consult with the appropriate experts to develop and provide educational materials to guide these conversations.

### *Non-hospice Spending During a Hospice Election*

AARP shares CMS' concerns about the reasons for the growth in overall non-hospice spending by almost one-third over a four-year span, which now totals \$1.4 billion in FY 2022. In the proposed rule, CMS emphasizes that it would be unusual and exceptional to see services provided outside of hospice for those individuals approaching the end of life and that "virtually all" care needed by the terminally ill individual would be provided by the hospice. We believe CMS needs to provide more information and perform additional analyses to determine whether this spending growth is inappropriate and thus these costs should be covered under the hospice benefit or whether this care is being appropriately requested by beneficiaries as care that is unrelated to the terminal illness for which the beneficiary elected hospice care. This is an important distinction and one that warrants more detailed and complete analysis. AARP recommends that CMS use its claims data to examine the billing pattern for these services and whether these services are related to the terminal illness indicated upon hospice election. CMS already has a claims mechanism in place to identify inappropriate payments during a hospice election. CMS could also conduct sample hospice audits to determine whether the non-hospice spending is related or unrelated to the terminal illness identified for the beneficiary upon hospice election.

As part of a broader claims analysis, CMS should also examine these utilization patterns to determine whether further action is needed to address whether most of this care should be provided under the hospice benefit or whether additional guidance/education to Medicare providers and beneficiaries on the use of certain services may be warranted.

### *Hospice Ownership Status*

AARP notes that ownership [trends](#) in the hospice industry can impact the care that Medicare beneficiaries receive. A recent [study](#) found that family caregivers of hospice patients "...reported substantially worse care experiences in for-profit than in not-for-profit hospices; however, there was variation in reported experiences among both types of hospices. Public reporting of hospice quality is important." This underscores the importance of transparency, collecting data on ownership and quality, using and analyzing that data, and making it available in easy-to-understand information for consumers and their families seeking hospice care to help them select a hospice provider that is right for them and will provide quality care.

Consistent with our [recent comments](#) to CMS on expansion of ownership transparency in the nursing home sector in response to CMS-6084-P,<sup>2</sup> many of these efforts could be applied to the hospice sector as well. We urge CMS to consider to what extent similar information should be made available to the public that could be helpful to beneficiaries and their families in selecting and receiving high quality hospice care. Here are some principles or concepts from our

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<sup>2</sup>Medicare and Medicaid Programs; Disclosures of Ownership and Additional Disclosable Parties Information for Skilled Nursing Facilities and Nursing Facilities

comments on the above nursing home proposed rule that that could be applied to the hospice sector:

- CMS should require that ownership information be true, correct, and complete and that information be easily accessible for beneficiaries receiving hospice, beneficiaries considering hospice, their family caregivers, and the public. We believe that self-reported information should be audited for accuracy and that reporters of inaccurate data should face appropriate enforcement action.
- CMS should take a more proactive role in monitoring hospices to encourage positive change. This should be done in a timely manner to improve quality, using ownership data, Hospice Cost Report Data, clinical quality metrics, and other appropriate data to understand the ongoing performance of individual hospices and large groups connected by common ownership.
- CMS also should require disclosure of owners within the parent company to reflect the complexity of ownership, increase transparency, and be able to hold accountable the parent companies of hospices.

CMS should continue its efforts to make ownership data for all Medicare-certified hospices publicly available. We applaud the CMS announcement on April 20, 2023, that it is releasing ownership data on more than 6,000 hospices as we believe this is an important step forward to promote and increase transparency of ownership information. We are concerned about the accuracy and accountability of the reported data and urge CMS to consider ways to ensure its accuracy. AARP also urges CMS to add ownership information about hospices that is already available on [data.cms.gov](https://data.cms.gov) to Care Compare, which would be helpful to consumers.

#### *Information to Support Family Caregivers*

AARP believes that it is essential to provide information to help Medicare beneficiaries and their family caregivers make informed decisions about hospice selection as well as the care that is provided in the hospice. To aid in the selection of a hospice, AARP believes it is imperative for individuals and their family caregivers to be educated on what hospice is and have access to detailed information about the hospice including ownership type, staffing levels, frequency of staff encounters, average and median length of stay, as well as the utilization of higher level of care.

AARP continues to believe that it is important to strengthen recognition, inclusion, and support of family caregivers in Medicare to aid in the day-to-day care of beneficiaries, recognizing that family caregivers are current and future Medicare beneficiaries. Family caregivers should be identified in electronic records (as well as paper records) of the person they are assisting so they can appropriately be part of their loved one's care team if a care or service plan depends on having a family caregiver. In some cases, this may mean identifying a primary family caregiver and/or other caregivers (including a health care agent or guardian) who take on particular roles or assist their loved ones with specific tasks. This is especially relevant in hospice, which is providing services and support directly to the Medicare beneficiary and their family. Family caregiver identification facilitates engagement, communication, and coordination with the caregiver, as well as the provision of caregiver support, as appropriate. Including this

information would be an important step for further development of quality measures related directly to family caregivers. The individual (or their representative, if appropriate) would be given the opportunity to identify their family caregiver(s), which is consistent with Health Insurance Portability and Accountability Act (HIPAA) requirements.

### RFI on Health Equity Under the Hospice Benefit

AARP firmly believes that ensuring health equity promotes better quality for all older adults and supports the Administration's initiatives to advance health equity regardless of the contributing factors that affect access to care. We believe that gathering data about race, ethnicity, and social determinants of health (SDOH) is essential for addressing health equity. We remain committed to working with CMS and other stakeholders to ensure all our nation's seniors have access to high quality hospice care.

In addition to identifying and measuring disparities, we believe that CMS needs to better understand the reasons why hospice care use is lower for racially and ethnically diverse beneficiaries compared to White beneficiaries. Almost 90 percent of beneficiaries in nonprofit hospices, for example, are White compared with only 7 percent Black and less than 2 percent for Hispanic and Asian beneficiaries.<sup>3</sup> In addition, a recent study showed racial differences in the use of hospice services between Black and White individuals with cardiovascular disease with Black individuals less likely to receive hospice care.<sup>4</sup> It is essential to not only collect data but to also understand and address the factors that may impede access or create reluctance to use hospice services; these factors are likely complex and multifaceted and may include cultural aspects, such as the role of a family caregiver.

In the proposed rule, CMS requested comment on a set of questions. We respond to those questions for which AARP can provide the most insight.

*What information can CMS collect and share to help hospices serve vulnerable and underserved populations and address barriers to access?*

An important component for improving equity in hospice care is ensuring health care providers are educated on multiple factors that may impact an individual and their family's understanding of hospice care as they engage in decision-making conversations. This includes but is not limited to access to quality hospice and health care services, recognition of potential provider bias that can impact what information is presented to an individual and their family caregiver as well as limited treatment options (i.e., pain management), and understanding of various cultural beliefs related to end-of-life.<sup>5</sup>

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<sup>3</sup> U.S. Government Accountability Office (GAO). *Medicare Hospice Care. Opportunities Exist to Strengthen CMS Oversight of Hospice Providers*. GAO-20-10. (Washington, D.C.: Oct. 18, 2019).

<sup>4</sup> Ornstein KA, Roth DL, Huang J. et al. Evaluation of Racial Disparities in Hospice Use and End-of-Life Treatment Intensity in the REGARDS Cohort. *JAMA Network Open*, 2020;3(8):e2014639. Doi10.1001/jamanetworkopen.2020.14629.

<sup>5</sup> Johnson KS. Racial and ethnic disparities in palliative care. *J Palliat Med*. 2013 Nov;16(11):1329-34. doi: 10.1089/jpm.2013.9468. Epub 2013 Sep 27. PMID: 24073685; PMCID: PMC3822363.

To improve provider understanding of cultural differences and other factors impacting utilization and access in racially and ethnically diverse communities, as part of its health equity framework, CMS could develop education tools highlighting cultural norms, including determining a patient's cultural identity, to facilitate discussions about hospice care. Additional resources should be developed to help understand how these cultural norms impact the delivery of hospice services in a manner that promotes access and utilization, recognizes cultural preferences, and addresses potential provider bias.

*What sociodemographic and SDOH data should be collected to effectively evaluate health equity in hospice settings?*

AARP supports the collection of sociodemographic and SDOH data. It is also important to distinguish between data that can be collected from claims information and data that can only be obtained directly from the beneficiary and/or family caregivers.

As a first step, AARP recommends using the standardized data elements to assess for SDOH including the related standardized patient assessment data elements (SPADEs) that are being collected across post-acute care (PAC). Although hospices were not included in the requirement in the Improving Post-Acute Care Transformation Act of 2014 (IMPACT Act), we believe that using the same data elements will help implementation for hospices and also allow CMS to evaluate hospice and post-acute care. CMS should also consider including a Caregiver Status SPADE. This data point would identify whether a Medicare beneficiary has a family caregiver (who may or may not be next of kin) and identify that individual to the hospice provider, including contact information. Absence of an identifiable caregiver may also serve as a marker for other social risk factors that influence individuals' outcomes. AARP has recommended a Caregiver Status SPADE previously for other PAC providers.

The SPADEs for the assessment of SDOH include ethnicity, race, preferred language, need for interpreter, health literacy, transportation, and social isolation. We believe that additional SDOH should also be collected, such as a Caregiver Status SPADE, housing, transportation, and food security, but some of these can be identified and incorporated over time. For sociodemographic data, we suggest the collection of gender, race/ethnicity, sexual orientation, income, occupation, education, and geographic location. In combination with administrative data from claims and medical records, CMS will be able to develop a more comprehensive view of health equity in hospice care.

*What are feasible and best practice approaches for the capture and analysis of data related to health equity?*

AARP recognizes the difficulties inherent in collecting data related to health equity. We recommend that any approach to collecting health equity data rely on the following principles:

- *Engage older adults and families in data collection:* Engaging older adults and families in data collection can help ensure that the data being collected is relevant and meaningful to those being served.

- *Ensure patient privacy:* Appropriate measures should be in place to protect patient privacy and confidentiality, including secure data storage and appropriate consent procedures. This also helps address issues around patient trust.
- *Apply culturally appropriate data collection methods:* Data collection methods should be tailored to the cultural and linguistic needs of the population being served, with attention to issues such as language barriers and health literacy.
- *Use a variety of data sources:* In addition to self-reported data, data should be collected from other sources, such as medical records and administrative databases, to provide a more comprehensive view of health equity in hospice care.
- *Collect data at multiple points in continuum of care:* Collecting data at different stages of hospice care (e.g., admission, during care, and after care) can help identify disparities and inform quality improvement efforts.

*What barriers do hospices face in collecting information on SDOH and race and ethnicity?*

AARP also recognizes the considerable challenges in collecting information on SDOH and race and ethnicity. These barriers include:

- *Patient Mistrust:* Older adults, particularly those from communities of color, may feel uncomfortable engaging with hospice staff around personal information which may make it challenging to collect accurate or complete data on SDOH and race and ethnicity.
- *Language and literacy barriers:* Hospices may serve older adults who speak different languages or have varying literacy rates, which, without provider education on how best to communicate, can present challenges in the collection of accurate or complete data on SDOH and race and ethnicity. There are also cultural and religious barriers that may make it difficult to collect such information.<sup>6</sup>
- *Limited staff training:* Hospice staff may not be trained to ask questions about SDOH and race and ethnicity or may not be comfortable discussing these topics with older adults and families.
- *Lack of access to data collection, analytics, and reporting resources:* Hospices may lack access to the necessary resources to collect, analyze, and report on SDOH data.

*What is needed to overcome those barriers?*

AARP believes that using SPADEs for the assessment of SDOH in the hospice care setting will allow CMS to collect standardized data that could be used to compare outcomes within hospice as well as compare quality within and across PAC settings. In addition to the use of a standardized approach to collecting SDOH data, hospices will need to invest in staff training. This includes training staff on how to collect, analyze, and report SDOH data, training on cultural competency and effective communication, or partnering with organizations that have the expertise to do so. We also believe in the importance and benefit of partnering with community

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<sup>6</sup> Dressler G, Cicolello K, Anandarajah G. "Are They Saying It How I'm Saying It?" A Qualitative Study of Language Barriers and Disparities in Hospice Enrollment. *J Pain Symptom Manage*. 2021 Mar;61(3):504-512; and Silva MD, Genoff M, Zaballa A, Jewell S, Stabler S, Gany FM, Diamond LC. Interpreting at the End of Life: A Systematic Review of the Impact of Interpreters on the Delivery of Palliative Care Services to Cancer Patients With Limited English Proficiency. *J Pain Symptom Manage*. 2016 Mar;51(3):569-80.

organizations. Hospices can partner with community organizations that cater to diverse populations to help collect data as well as build trust with community members around the benefits of hospice care.

AARP appreciates your consideration of our comments and urges you to incorporate them into the final rule, including provisions regarding family caregivers. We urge you to focus on Medicare beneficiaries and their family caregivers as you finalize this regulation. If you have any questions, please contact me or Rhonda Richards on our Government Affairs staff at [r-richards@aarpp.org](mailto:r-richards@aarpp.org).

Sincerely,

A handwritten signature in black ink, appearing to read "David Certner", with a long horizontal flourish extending to the right.

David Certner  
Legislative Counsel and Legislative Policy Director  
Government Affairs