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REPORT TO THE CONGRESS

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Medicare Beneficiaries'  
Access to Hospice



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Medicare Beneficiaries'  
Access to Hospice

**MEDPAC** Medicare  
Payment Advisory  
Commission

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# R E C O M M E N D A T I O N S

- 1** The Secretary should evaluate hospice payment rates to ensure they are consistent with the costs of providing appropriate care.

\* YES: 14 • NO: 0 • NOT VOTING: 0 • ABSENT: 3

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- 2** The Secretary should research differences in the care and resource needs of hospice patients and determine whether a case-mix adjusted payment system for hospice care is feasible. He also should study ways to establish a high-cost outlier policy.

YES: 14 • NO: 0 • NOT VOTING: 0 • ABSENT: 3

\*COMMISSIONERS' VOTING RESULTS

**T**he Congress asked the Medicare Payment Advisory Commission (MedPAC) to report on beneficiaries' access to and use of the hospice benefit, including delays in the time (relative to death) of entry into hospice programs and urban and rural differences in beneficiaries' use of hospice. This report gives our response to these questions.

We assessed two indicators of access: the use of services by beneficiaries and supply of providers. From 1992 to 2000, the number of beneficiaries using hospice tripled and the number of hospice providers nearly doubled. In 2000, 23 percent of all Medicare decedents and 60 percent of those who died of cancer used hospice services. We also found that beneficiaries living in rural areas have increased their use of hospice care relative to their urban counterparts. The percentage of rural beneficiaries that used hospice more than tripled from 1992 to 2000, compared with a doubling of urban hospice users. In addition, in 2000, less than 1 percent of decedents lived in areas with no available hospice.

The substantial growth in the use of hospice has been accompanied by an increase in the fraction of hospice patients dying within one week of admission—from 21 percent in 1992 to 30 percent in 2000. This has led some observers to conclude that beneficiaries have difficulty in accessing hospice care. Two factors associated with late referrals—the difficulty of predicting death and beneficiaries' unwillingness to give up curative care—are unlikely to have changed during the 1990s. However, nondebilitating therapies—which allow patients to extend curative treatment longer than they might have otherwise—became more available during this period. Changes in the composition of the population using hospice also confound interpreting trends in length of stay.

Although Medicare's payment policies do not appear to explain the increase in short stays—Medicare pays for hospice on a per diem basis—the Commission is concerned that Medicare's payment rates for providing hospice care may differ from the efficient costs of care for hospice patients, as payment rates are based on information from a demonstration project conducted in the early 1980s. Accordingly, we recommend that the Centers for Medicare & Medicaid Services (CMS) reevaluate hospice rates to ensure their adequacy. Better information is needed about the services patients need and use, and about differences in use of services among hospice patients. Research on these topics is needed to lay a foundation for a payment system that accounts for differences in the resources needed to care for patients. It also will help improve payments for costly patients, whether in concert with the existing payment policy or with a case-mix adjusted payment system.

## **What is hospice?**

Terminally ill beneficiaries—those certified by an attending physician and a hospice medical director to have life expectancy of six months or less (if the disease runs its normal course)—may elect to receive hospice care. To be eligible for the rich package of hospice services, beneficiaries must give up other Medicare services related to curative treatment of their terminal illness. For beneficiaries who elect hospice, Medicare still covers treatment of illnesses and injuries unrelated to the terminal illness. Beneficiaries can disenroll from hospice at any time.

Hospice care aims to help terminally ill patients remain in their homes and live relatively normal lives in their last months. It does so by providing a broad array of services that expand upon those generally covered by Medicare (see appendix). For example, hospice provides patients with drugs and biologicals for pain control and symptom management, and furnishes homemaker services that are not covered for home health care patients.

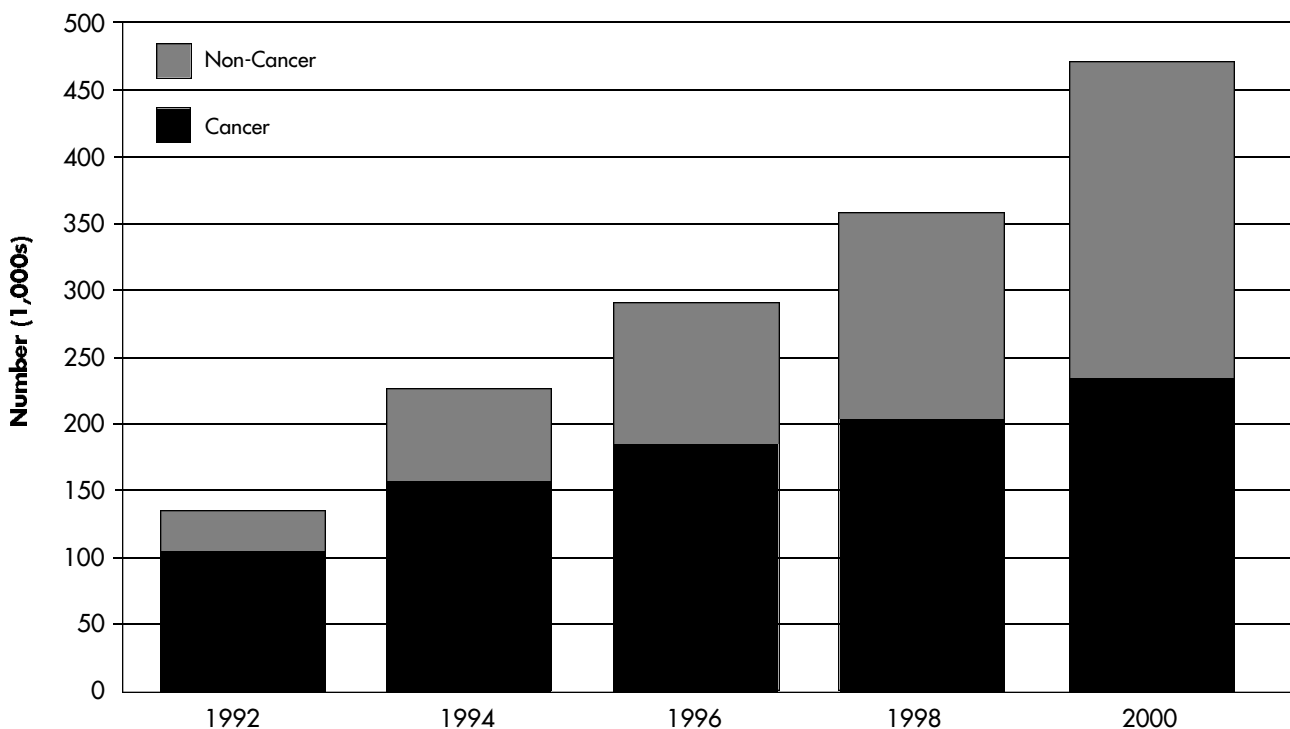
## Indicators of access

Two indicators of access are beneficiaries' use of services and the supply of providers. In general, beneficiaries appear to have greater access to hospice care today than in the early 1990s, as evidenced by the dramatic increase in both of these indicators (GAO 2000, Hogan 2002).<sup>1</sup>

The number of Medicare beneficiaries using hospice services tripled from 1992 to 2000 (from 143,000 to 464,000), an average annual increase of 16 percent (Hogan 2002) (Figure 1). Twenty-three percent of Medicare beneficiaries who died in 2000 used hospice, compared with less than 9 percent in 1992; 60 percent of beneficiaries who died of cancer in 2000 used hospice services (Hogan 2002, Hogan 2001).

**FIGURE 1-0**

**New hospice patients by diagnosis, 1992-2000**



Source: Direct Research, LLC.

<sup>1</sup> To respond to the Congress's request, we contracted with Direct Research, LLC to review the literature and analyze data from administrative records and the Medicare Current Beneficiary Survey (Hogan 2001). The Summit Business Group, LLC, another contractor, interviewed key informants familiar with hospice and convened a focus group of experts to develop and prioritize ways to improve beneficiaries' access to hospice care (Mahoney 2002).

Hospice use increased among all groups of beneficiaries from 1992 to 2000. In 1992, the typical hospice user was a beneficiary with a diagnosis of cancer who lived at home in an urban area. By 2000, the profile of the typical user shifted somewhat, with the greatest growth in the numbers of beneficiaries with non-cancer diagnoses and those living in nursing homes or rural areas.

Beneficiaries with non-cancer diagnoses (such as heart disease or Parkinson's disease) were among the fastest-growing groups of hospice patients. Hospice users with non-cancer diagnoses represented 49 percent of the total in 2000, compared with 24 percent in 1992 (Hogan 2002). During this period, patients with non-cancer diagnoses increased 557 percent, compared with a 117 percent increase in cancer patients.

Use of hospice by beneficiaries living in nursing homes also grew dramatically, from 11 percent to 36 percent (Hogan 2001, Hogan 2002). The growth in hospice use by nursing home residents reflects both the rise in hospice users with non-cancer diagnoses and the prevalence of nursing home residents with non-cancer diagnoses who are eligible for hospice. For example, in 1998, 52 percent of hospice enrollees with non-cancer diagnoses had some nursing home use in the year of death, compared with 30 percent of enrollees with cancer diagnoses.

The percentage of rural beneficiaries using hospice increased dramatically relative to the fraction of urban hospice users. From 1992 to 2000, the percentage of rural decedents using hospice tripled (from 6 percent to 19 percent) while urban decedents using hospice services more than doubled (from 10 percent to 25 percent) (Hogan 2002, Hogan 2001). In 2000, beneficiaries living in rural areas used hospice at 75 percent of the urban rate; in 1992, rural beneficiaries used hospice at 57 percent of the urban rate.

The number of hospices participating in the Medicare program increased by 89 percent (from 1,208 to 2,283) from 1992 to 2002. From 1992 to 1999, the number of for-profit hospices and hospices serving more than 500 beneficiaries per year increased at the fastest rates—293 and 216 percent, respectively. Hospices in rural areas experienced greater growth than urban hospices—116 percent versus 64 percent (GAO 2000). Nationally, less than 1 percent of decedents lived in areas with no hospice available in 2000 (Hogan 2001).<sup>2</sup> Counties without hospices were sparsely populated, less likely than counties with hospices to have a hospital, and predominantly located in totally rural areas (not adjacent to urban areas and having no town exceeding 2,500 people). In four states (Montana, South Dakota, Wyoming, and Nebraska) between 10 and 30 percent of rural Medicare beneficiaries lived in counties without apparent access to hospice care.

Despite the increases in use and availability of hospice care, two groups of beneficiaries use hospice care less frequently—minority beneficiaries and people without supplemental insurance coverage (such as Medigap, Medicare+Choice, retirement coverage, or Medicaid) (Hogan 2001). Low use rates could suggest access problems for these groups or could result from other causes. For example, hospice experts interviewed for this study attributed lower use among minority beneficiaries to their cultural beliefs and attitudes toward health care (Mahoney 2002). The literature also supports cultural attitudes as the reason minority individuals do not use hospice as frequently as those who are white (Krakauer et al. 2002). As for people without supplemental insurance, their less frequent use of hospice is more difficult to interpret because copayments for hospice care are minimal.

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2 Counties were identified as having evidence of hospice service if 5 percent of hospice claims revealed at least two beneficiaries residing in that county who used hospice at some time during the period of 1993 to 1999, the CMS provider of service file showed at least one active hospice provider headquartered in that county in 2000, or some member of the National Hospice and Palliative Care Organization reported providing service to that county.

### **Other access issues**

A MedPAC contractor interviewed people knowledgeable about hospice to learn about potential access problems not detected by our two indicators (beneficiary use and supply of providers). Interviewees told the contractor that despite the rapid growth in use of hospice, some beneficiaries experience difficulty in accessing care, including:

- older beneficiaries, and
- people receiving palliative chemotherapy, radiation, or surgery.

Our informants hypothesized that older beneficiaries may have difficulty accessing hospice care because hospices may be reluctant to admit patients with no caregivers or frail caregivers (Mahoney 2002). Further, they reported that some hospices, as a policy, do not admit beneficiaries without competent caregivers.

Patients using chemotherapy, radiation therapy, or surgery constitute another category of beneficiaries our key informants believed to be at risk of having access problems (Mahoney 2002). Some hospices use very strict definitions of palliative or non-curative care that do not include chemotherapy or radiation. Our informants reported that some hospices also may be reluctant to admit such patients because of concern about the costs of providing the therapies. On the other hand, patients undergoing curative chemotherapy or radiation may not have accepted the proximity of their death or be willing to give up curative care and, thus, would not qualify for hospice care.

### **Short hospice stays**

Some observers express concern that short hospice stays indicate that beneficiaries have problems accessing hospice. From 1992 to 2000, the fraction of hospice patients dying within one week of admission increased from 21 percent to 30 percent (Hogan 2002). A diagnosis of congestive heart failure, myocardial infarction, or lung cancer significantly predicted admission to hospice within two weeks of death (Hogan 2001). The difficulty of predicting death for people with congestive heart failure or myocardial infarction and the rapid decline of patients with lung cancer may help explain why patients with these conditions would be more likely to have shorter hospice stays.

We conclude that Medicare payment policies are not a primary contributor to beneficiaries having short hospice stays. Instead, more important main causes of late referrals appear to be the difficulty of making prognoses of death within six months, unwillingness of beneficiaries to give up curative care, and the greater availability of non-toxic therapies that make continuing treatment more palatable.

Our key informants also reported that many physicians are reluctant to identify their patients as having a six-month prognosis (Mahoney 2002). The literature supports this reluctance (Christakis 2000). In addition, research has shown that only 20 percent of prognoses are accurate and 63 percent overestimate survival time; the more familiarity physicians have with patients, the more inaccurate the prognosis (Christakis and Lamont 2000).



Medicare policy may have contributed to short stays in the past, but a key problem appears to have been resolved. In response to hospices' concern about fiscal intermediaries' interpretation of the 6-month prognosis rule, CMS in 2000 (then the Health Care Financing Administration) clarified that the rule does not preclude beneficiaries who meet the eligibility criteria from receiving hospice service longer than six months (DeParle 2000). In addition, the Medicare, Medicaid and SCHIP Benefits Improvement and Protection Act of 2000 clarified that certification of a 6-month prognosis is based on the physician's or hospice medical director's clinical judgement regarding the normal course of the individual's terminal illness. It may take more time for the health care industry to adapt to the clarification of policy, however.

Patients certified by their physicians as eligible for hospice may choose to continue curative care. The availability of less toxic therapies is likely an important factor in patients' decisions to postpone the election of hospice care (Mahoney 2002). For example, chemotherapy that is not debilitating may be attractive to some patients even if it offers little clinical chance of successful treatment.

Data from 1992 to 1998 also show that receiving home health services predicted short hospice stays (Hogan 2001). The implementation in 2000 of the prospective payment system for home health may have altered the relationship between home health use and short hospice stays, however. Changing from a payment system in which home health agencies (HHAs) were paid for each visit furnished to a system with case-mix adjusted per-episode payments may have increased HHAs' willingness to refer appropriate patients to hospices. Also, HHAs are now required to report a prognosis for each patient. According to our contractor's focus group, making prognoses may have made providers more aware of beneficiaries' eligibility for and ability to benefit from hospice services, which may lead in turn to earlier referrals in the future. It is also possible, however, that some patients will continue to prefer home health services with familiar providers to hospice services with new providers.

## **Medicare payment rates need to be evaluated for adequacy**

Notwithstanding improvement in access in the past decade, Medicare's payment rates must be adequate to protect beneficiaries' continued access to care without financial burdens on them or on taxpayers.

Medicare pays a fixed amount to hospices for each day a beneficiary is eligible and under hospice care, regardless of the services furnished on any given day. These per diem payment rates are based on a fee schedule with separate rates for four broad categories of care: routine home care, continuous home care, inpatient respite care, and general inpatient care.<sup>3</sup> Patients are assigned to these categories based on the type of care they actually receive each day; the default category is routine home care.

Hospice payment rates are based on information from a Medicare demonstration project completed in the early 1980s. Although the rates have been updated for inflation over time, they probably are not consistent with the costs that efficient hospices incur in furnishing care. Rapid growth of providers suggests that rates are sufficiently generous, although the hospice industry maintains that rates are too low. To resolve this issue, rates must be reevaluated as soon as cost reports are available for hospices.<sup>4</sup>

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3 Inpatient respite care provides short-term relief for patient caregivers. General inpatient care may be necessary to perform procedures for pain control or symptom management when they cannot be furnished in other settings.

4 Before April 1, 1999, hospices were not required to submit cost reports. CMS estimates that cost reports will be available beginning in June 2002.

## RECOMMENDATION 1

### **The Secretary should evaluate hospice payment rates to ensure they are consistent with the costs of providing appropriate care.**

Because hospice care has changed since the 1980s, this task involves more than estimating the relationship of payments to costs, and should include an assessment of the cost base for the rates. The evaluation should determine the efficient costs of furnishing appropriate high-quality hospice care, including new pain medications and other palliative treatments.

A number of issues also require attention when rates are evaluated for payment adequacy, such as whether rural hospices have higher costs than their urban counterparts. Our key informants suggested that rural hospices may have higher costs because of their location in sparsely populated areas where it is difficult to attract appropriate personnel, travel distances restrict the number of home-based patients a hospice employee can see in a day, patient volume is low, and infrastructure is limited. When cost reports are available, CMS will be able to determine empirically whether cost differences exist and to which factors they are attributable.

Our key informants also reported that short stays disadvantage hospices because they cannot recoup the costs of admitting patients and providing services close to death. CMS will be able to determine whether payments are adequate for hospices that have disproportionate frequencies of short stays. If payments are inadequate, higher rates could be paid for the first and last days of a hospice stay.

Another issue that may merit attention is whether hospices should be paid the same rate when furnishing care to nursing home residents and patients at home. The Office of the Inspector General (OIG) found that hospice patients in nursing homes received fewer services than similar patients in their homes and has expressed concern that rates are the same for both types of patients (OIG 1997).

### **Additional research on differences in hospice patients is needed**

Hospice payment rates are currently the same for all types of patients, with no adjustment for case mix. However, some patients may be systematically more costly than others, while others are less costly. Before a case-mix adjusted payment system can be developed, however, policymakers need more information on the care patients need, the services they receive, and differences among types of patients. For example, the care that cancer patients require may be very different than that needed by patients with non-cancer diagnoses. In addition, lung cancer patients frequently have shorter stays and may require different resources than other cancer patients because of the nature of their illness. Systematic differences also may exist among non-cancer patients, such as those with congestive heart failure or AIDS. These questions cannot be answered without research.

Because the hospice payment rates are currently the same for all patients, some hospices may avoid patients who need more care or more expensive care than the average patient (Huskamp et al. 2001). For example, our key informants reported that patients receiving palliative chemotherapy or radiation may have problems accessing care because these interventions can be costly (Mahoney 2002). Older beneficiaries who have no caregiver also may be perceived as being costly because they may need more services than the average patient. Providers might be more willing to admit potentially costly patients if they could be assured of recovering most of their costs.

## RECOMMENDATION 2

**The Secretary should research differences in the care and resource needs of hospice patients and determine whether a case-mix adjusted payment system for hospice care is feasible. He also should study ways to establish a high-cost outlier policy.**

A case-mix adjusted payment system seems conceptually possible and would offer the advantage of tying payment rates more closely to patients' resource needs. Research on whether such a system is feasible, however, needs to occur before a decision is made to develop it. Research might provide not only a foundation on which to build a case-mix adjusted payment system but also secondary benefits. For example, it may provide information that improves physicians' abilities to make prognoses of death and to provide high-quality care for terminally ill patients.

Research on outlier policies should include both methods that can be implemented with existing payment policy and methods that might be used with a case-mix adjusted payment system. A high-cost outlier policy, in concert with the existing payment system, could result in hospices being more willing to accept patients they perceive as potentially costly. Many hospices are small, with fewer than 100 patients per year, and may be unable to balance more costly patients against less costly ones (GAO 2000). An outlier policy constructed with a relatively low fixed-loss threshold and reimbursement of a relatively high proportion of costs above the threshold would be sensitive to these hospices. For example, the threshold and cost sharing for home health outlier payments might be an appropriate model to study—the fixed-loss threshold is 113 percent of payment and home health agencies are reimbursed at 80 percent of costs above the threshold. If a case-mix adjusted payment system is feasible, it also should include a high-cost outlier policy. ■

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**A P P E N D I X**

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**Medicare hospice services  
and payment rules**

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## Medicare hospice services and payment rules

Medicare covers hospice care for beneficiaries who elect the benefit and are certified by an attending physician and a hospice medical director to have a life expectancy of six months or less if the disease follows its usual course. Patients who opt for hospice care receive palliative care and forgo curative treatment related to the terminal condition. Medicare will continue to cover illnesses and injuries unrelated to the terminal condition and outside the hospice plan of care. Medicare covers the following services under its hospice benefit:

- skilled nursing care
- medical social services
- physician services
- patient counseling (dietary, spiritual and other)
- short-term inpatient care
- medical appliances and supplies
- drugs and biologicals for pain control and symptom management
- home health aide services
- homemaker services
- therapy (physical, occupational, and speech)
- inpatient respite care
- family bereavement counseling

The hospice benefit is divided into periods. The first two periods are 90 days each. Subsequent periods are 60 days. Beneficiaries must be recertified at the beginning of each period; as long as they qualify for the benefit, there is no limit on the number of periods beneficiaries may use hospice care. At any time, beneficiaries may opt out of hospice care and seek curative treatment. They also may change their hospice once during each period. Families may receive bereavement counseling for up to 13 months following a patient's death.

### Payment for hospice services

Medicare pays hospices a fixed rate for each day beneficiaries are eligible and under the care of a hospice. The per diem rates are predetermined by a fee schedule with four categories of care: routine home care, continuous home care, inpatient respite care for the short-term relief of patients' caregivers, or general inpatient care as necessary for pain control or symptom management. The labor portions of per diem rates are adjusted by a version of the hospital wage index to account for differences in local wage rates in the locations of beneficiaries receiving services. Total inpatient care days per year provided by any one hospice may not exceed 20 percent of all patient care days (excluding patient care days spent as a custodial resident of a nursing home).

Aggregate reimbursement to any hospice is subject to an annual cap. The limit for each agency is determined by a fixed rate per beneficiary (\$16,651 for fiscal year 2002) multiplied by the number of new beneficiaries enrolled by the hospice during the fiscal year. The national per diem rates for each payment category of care are updated annually by the acute care hospital market basket index.

Beneficiaries may have some coinsurance payments for hospice care. They are liable for a maximum \$5 copayment for drugs or biologicals furnished by the hospice while they are not receiving inpatient care. They also are liable for 5 percent of the rate for a day of inpatient respite care, subject to an annual limit equal to the inpatient hospital deductible.

**Conditions of participation**

To participate in Medicare, a hospice must be able to provide a wide range of services, some of which are considered core services. These core services—nursing services; medical social services; and bereavement, spiritual, and dietary counseling—must be provided by employees of the hospice. Hospice employees also may provide the non-core services (such as home health aide or physician services) directly, or the hospice may contract to provide them. Rural hospices in operation before 1983 may be exempt from the requirement to provide nursing services directly. Some rural hospices also may be exempt from the requirement to provide therapy services or dietary counseling. Unique among providers participating in the Medicare program, hospices must employ unpaid volunteers for a minimum of 5 percent of total patient care hours.■



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**Commissioners' voting  
on recommendations**

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## Commissioners' voting on recommendations

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In the Medicare, Medicaid, and SCHIP Benefits Improvement and Protection Act of 2000 (BIPA), the Congress required MedPAC to call for individual Commissioner votes on each recommendation, and to document the voting record in its report. The information below satisfies that mandate.

### Recommendation 1

The Secretary should evaluate hospice payment rates to ensure they are consistent with the costs of providing appropriate care.

*Yes: Braun, DeBusk, Feezor, Hackbarth, Loop, Muller, Nelson, Newhouse, Newport, Raphael, Reischauer, Smith, Stowers, Wakefield*

*Absent: Burke, Rosenblatt, Rowe*

### Recommendation 2

The Secretary should research differences in the care and resource needs of hospice patients and determine whether a case-mix adjusted payment system for hospice care is feasible. He also should study ways to establish a high-cost outlier policy.

*Yes: Braun, DeBusk, Feezor, Hackbarth, Loop, Muller, Nelson, Newhouse, Newport, Raphael, Reischauer, Smith, Stowers, Wakefield*

*Absent: Burke, Rosenblatt, Rowe*



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