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1. **Introduction**

In response to significant changes in hospice utilization that have occurred since the Medicare hospice benefit was established in 1983, and to recommendations by the Medicare Payment Advisory Commission (MedPAC) and others for updates to the hospice payment system, section 3132(a) of the Affordable Care Act (Patient Protection and Affordable Care Act, 2010) requires the Secretary of Health and Human Services (HHS) to reform Medicare’s payment system for hospice care. Hospice payment reform includes the Secretary collecting “additional data and information as the Secretary determines appropriate to revise payments for hospice care” (Section 3132(a) of Affordable Care Act, 2010). These additional data collection efforts may include:

- Charges, payments, costs, number of days, and number of visits of hospice care attributable to each type of service
- Number of days of hospice that are attributable to Medicare beneficiaries enrolled under Part A
- Charitable contributions and other revenue of hospice providers
- Type of practitioner providing the hospice visit
- Length of the visit and other basic information with respect to the visit

Based on analyses from these data (which the Secretary is to have begun collecting no later than January 1, 2011), HHS is required to implement revisions to the hospice payment methodology no earlier than October 1, 2013. The Affordable Care Act mandates that the revisions to the hospice payment system “shall result in the same estimated amount of aggregate expenditures under this title for hospice care furnished in the fiscal year in which such revisions in payment are implemented as would have been made under this title for such care in such fiscal year if such revisions had not been implemented” (Section 3132(a) of Affordable Care Act, 2010). That is, that the revisions be budget neutral for the first year.1

The Centers for Medicare and Medicaid Services (CMS) contracted with Abt Associates, teaming with the University of Colorado Division of Health Care Policy and Research, to convene a technical expert panel (TEP) to provide insights regarding reform of the Medicare hospice payment system. The Office of the Assistant Secretary of Planning and Evaluation (ASPE) provided empirical analyses as a foundation of understanding the current hospice environment for the TEP discussions. In addition Abt Associates used this analysis to inform the development of a study design that detailed the analytic approach that will be used to satisfy the goals of hospice payment reform. This work was conducted under the original “think tank” hospice contract (HHSM-500-2005-00018I TO00002).

Through a new “study” contract awarded to Abt Associates in September of 2011, the Centers for Medicare & Medicaid Services (CMS) is now developing payment reform options for the Medicare hospice payment system (HHSM-500-2005-0001 BI HHSM-500-T0004). This study contract has two subcontractors including Brown University and Social & Scientific Systems, Inc. who will be

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1 The law does not provide HHS with the authority to change the eligibility and coverage requirements under the hospice benefit. We also note that the Affordable Care Act makes additional changes to the hospice program that are unrelated to its payment program (for example, see Sections 3034, 3132(b), 3140, and 10326) which are not discussed in-depth in this document.
assisting Abt Associates and CMS with hospice payment reform efforts. Under this contract, the project team will conduct comprehensive data analyses, payment modeling, impact analyses, regression analyses, continually review the hospice peer-reviewed literature, update the “think tank” literature review and provide the necessary operational and rule-making support required for CMS to meet the statutory mandate of hospice payment reform.

The purpose of the review below is to provide background on the current hospice payment system and to present relevant research informing hospice payment reform. It is organized around the following policy goals and related research questions:

(1) **Describing growth and change in the hospice industry.**
   - What recent trends in hospice utilization are in keeping with the original payment system?
   - How effective is the current payment system in promoting access to appropriate care?
   - In what ways are Medicare hospice costs exceeding the cost of conventional care?

(2) **Aligning reimbursement with resource use.**
   - Under what circumstances does the hospice payment system accurately reimburse providers for the reasonable and necessary costs of care?
   - What are the effects of patient characteristics, site of service and other factors on the relationship between cost and reimbursement?
     - How should a reformed payment system take these factors into account?

(3) **Identifying payment system vulnerabilities.**
   - What are the vulnerabilities or perverse incentives that encourage overuse or underuse of hospice care?
   - What considerations are important in reforming the payment system to minimize perverse incentives without unduly impeding access to hospice care?

(4) **Responding to proposals for payment reform.**
   - How should the payment system be reformed to minimize perverse incentives without impeding access?
   - What is the evidence to support payment reform proposals?

This document describes the following:

(Section 2): Includes a description of the literature review search methodology.

(Section 3): Provides a brief background and overview of the Medicare hospice program.

(Section 4): Describes hospice-related Affordable Care Act legislation and current hospice data collection efforts, including hospice quality improvement initiatives.

(Section 5): Presents comprehensive findings from the literature related to each of the research questions that are stated in the section above.

(Section 6): Describes potential study limitations that should be considered when using the research studies cited in this review to inform hospice payment reform.
(Section 7): Provides a short summary of the findings for each research question that was investigated.

(Section 8): Includes a short acknowledgement section to recognize additional individuals who contributed to the development of this document.

(Section 9): Lists the articles, publications and reports cited in this review.

(Section 10): Presents the search terms that were used to conduct the literature review search.
2. Methodology

This review includes peer-reviewed English language journal articles published between January 1, 2000 and December 1, 2012, as well as select articles prior to 2000 and reports published during the same time period by MedPAC, CMS, U.S. Government Accountability Office (GAO) and HHS Office of Inspector General (OIG).

PubMed was utilized to search for peer-reviewed publications. The Medical Sub-Heading (MeSH) search terms used are shown in Appendix A along with the number of sources that were found using those terms and the number of sources actually cited in this review, by category. Additional articles and reports were added to the review after conducting reference reviews of identified publications as well as searching the CMS, OIG, GAO and MedPAC websites.

The primary criteria for including sources in this review were that (1) they had to be related to end-of-life care for Medicare hospice beneficiaries, and (2) were associated with one of the following topics:

- Access to care
- Health care utilization
- Cost of end-of-life care
- Variation in use of hospice care
- Variation in cost of end-of-life care
- Hospice site of service
- Hospice provider characteristics
- Hospice service patterns

Less relevant publications were eliminated. These included:

- Letters to the editor
- Studies focused on issues other than hospice access, utilization, cost, or reimbursement.
- Statistical reports superseded by more recent data
- Qualitative studies
- Studies with a very small number of subjects (fewer than 20)

Sources were screened by first reviewing the content of publication abstracts, then reviewing the full text of documents that appeared relevant. Through screening, more than one thousand potential sources were reduced to 84 references that are cited in this review of the literature.

After presenting the initial review to the TEP in June of 2011, TEP members identified additional relevant research studies that were later incorporated into the review. Similarly, additional research studies were added to the review at the recommendation of Brown University’s Center for Gerontology and Health Care Research, after they completed an independent critique of this work. Additionally, this review is updated on a quarterly basis and currently reflects peer-reviewed information related to hospice payment reform published as of December 2012.
Medicare’s hospice program came into existence in 1983 following enactment of the Tax Equity and Fiscal Responsibility Act of 1982 (Tax Equity and Fiscal Responsibility Act, 1982). The benefit, covered under Medicare Part A, provides palliative care and support services to patients primarily in their home. To be eligible for the Medicare hospice benefit, an individual must be certified by a physician as terminally ill and have Medicare Part A. Terminal illness is defined as a medical prognosis that the patient’s life expectancy is six months or less if the illness runs its normal course (Social Security Act §1861). The benefit was designed to provide end-of-life care to Medicare beneficiaries who want to forgo intensive medical interventions during this time. In addition to the goal of providing patients with a choice in end-of-life care, Congress expected that the hospice benefit would result in lower costs to the Medicare program (MedPAC, 2009). Beneficiaries elect the hospice benefit and in doing so forgo curative treatment for their terminal and related conditions, although they may still receive regular Medicare coverage for conditions unrelated to their terminal condition (CMS, 2010a). A broad array of services for the terminal illness and related conditions are covered under the hospice benefit, including nursing and physician care; hospice aide and homemaker services; drugs for palliative purposes; physical, occupational and speech therapies; medical equipment and supplies; short-term inpatient care, including respite care; counseling services including spiritual counseling; and bereavement and support services for the family (CMS, 2010a).

### 3.1 Benefit Periods

Hospice care is available for two periods of 90 days and an unlimited number of subsequent 60 day periods. For the first 90 day period of hospice coverage, the hospice must obtain a certification of the terminal illness for the patient from the medical director of the hospice or the physician member of the hospice interdisciplinary group, and the individual’s attending physician, if the patient has an attending physician. For each subsequent benefit period, a hospice physician must recertify the terminal illness (CMS, 2011b). A beneficiary may switch to another hospice one time during a benefit period, and can choose to revoke from hospice at any time (CMS, 2011b).

### 3.2 Demographic Information

In 2009, 95% of all Medicare hospice users were aged 65 or older, and 47% were aged 85 years old or older (CMS, 2010b). Almost 60% of hospice users are female and 88% are white (CMS, 2010b). Forty six percent of Medicare Advantage decedents compared to 41% of Fee-For-Service (FFS) decedents used hospice in 2009 (MedPAC, 2011). According to data collected from provider members of the National Hospice and Palliative Care Organization (NHPCO), home remained the most common site of death in 2010 for hospice decedents with 67% of patients dying in a home (41% in a private residence, 18% in a nursing home, and 7% in a residential facility), 22% in an inpatient hospice facility and 11% in an acute care hospital (NHPCO, 2011).²

² Due to rounding, these numbers do not total 100%.
3.3 Levels of Care, Payment Rates and Hospice Caps

Payment is made to a Medicare participating hospice for each day that a patient remains in hospice regardless of the amount of services furnished on a given day. Payment is calculated using one of four prospectively determined payment rates based upon the level of care and intensity of services that are provided by the hospice for the patient’s terminal and related conditions (CMS, 2010a).

The four levels of care are: routine home care (RHC), continuous home care (CHC), inpatient respite care (IRC) and general inpatient care (GIP). The payment rates by level of care are shown in Table 1, below. RHC is the most common level of care provided, accounting for more than 95% of hospice care days (MedPAC, 2011). The RHC level of care is provided in the patient’s home, including when the patient’s home is a nursing facility or other institutional setting. The CHC level of care is provided in the home during periods of crisis when a patient requires continuous care to achieve palliation or management of acute medical symptoms. To qualify for this level of care a patient must require a minimum of 8 hours of predominantly nursing care within a 24-hour period. The IRC level of care is provided in an approved facility as needed on an occasional basis to relieve the family or other caregivers for up to five consecutive days. The GIP level of care is provided in an approved inpatient facility when the patient requires pain and symptom management, which cannot be managed in the home (CMS, 2011b).

There are two caps that apply to Medicare hospice reimbursements:

1) The number of days of inpatient care the hospice may furnish is limited to not more than 20% of total patient care days (the inpatient cap) (CMS, 2010a); and

2) An aggregate payment cap amount which limits the amount of Medicare payments a provider may receive in an accounting year. The aggregate payment cap amount is calculated by multiplying the number of hospice beneficiaries during the accounting year by a per-beneficiary “cap amount.” There are two methods for counting the beneficiaries. The patient-by-patient proportional method counts only that fraction which represents the portion of a patient’s total days of care in all hospices and all years that was spent in that hospice in that cap year. The streamlined method counts those beneficiaries who received care from a single hospice in the initial year of election only. However, when a beneficiary receives care from more than one hospice, he or she is counted using the patient-by-patient proportional method. Which method a hospice uses depends on a number of factors, as described in chapter nine, section 90 of the Medicare Benefit Policy Manual (CMS, 2012b). The aggregate payment cap is then compared with actual aggregate payments made to the hospice during the cap year; any payments in excess of the cap are considered overpayments and must be refunded to Medicare by the hospice (CMS, 2011a).

Table 1: Basic Payment System for Hospice Care FY 2012, Before Wage Adjustment

<table>
<thead>
<tr>
<th>Level of Care</th>
<th>Payment Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Routine home care (RHC)</td>
<td>$151.03 per day</td>
</tr>
<tr>
<td>Continuous home care (CHC)</td>
<td>$881.46 per day or $36.73 per hour</td>
</tr>
<tr>
<td>Inpatient respite care (IRC)</td>
<td>$156.22 per day</td>
</tr>
<tr>
<td>General inpatient care (GIP)</td>
<td>$671.84 per day</td>
</tr>
<tr>
<td>Aggregate reimbursement cap per beneficiary served</td>
<td>$25,377.01</td>
</tr>
<tr>
<td>Inpatient days cap</td>
<td>20% of total days of service</td>
</tr>
</tbody>
</table>

Sources: CMS (2011c).
3.4 Overview of CMS’ Payment Adjustments Unrelated to Changes in Hospice Care

The hospice per diem payment rates for the four levels of hospice care were defined in the 1983 Hospice Care proposed and final rules (48 FR 38146, August 22, 1983 and 48 FR 56008, December 16, 1983, respectively) at the inception of the benefit. The law requires CMS to update hospice payment rates annually by the inpatient hospital market basket to account for inflation, unless otherwise directed by Congress (Social Security Act §1814). Payment rates are also adjusted to reflect local differences in area wage levels using a hospice specific wage index, which is based on hospital wage data (Federal Register, 1983, 2008a, 2008b). Since the passing of the Affordable Care Act, CMS is now required to apply a productivity adjustment to the hospital market basket. However, other than these adjustments for inflation wage differences and productivity, CMS has not revised the hospice payment system to reflect changes in the provision of hospice care since the system was first developed in the 1980s (MedPAC, 2010b).
4. Recent Hospice Related Policy and Data Collection Efforts

Until recently, Medicare required hospice providers to report only limited information on their claims (i.e., number of days of patient care by the four hospice care categories), and there were no data available on resources use or content, duration, or outcomes of the hospice services they provided (MedPAC, 2008). The unavailability of detailed data hindered Medicare’s ability to monitor and examine the hospice program and ensure it was effectively managed. This section provides a discussion of new data collection efforts.

4.1 New Data Collection Efforts

Beginning in January of 2007, and in response to an increase in the provision of hospice care in institutional settings such as nursing homes, CMS required the reporting of site of service on hospice claims in order to more accurately track location of care provided (CMS, 2009b). More recently, CMS began to require reporting of the number of visits by discipline by site of care, and, as of January 2010, visit length (to the nearest 15 minute increment) by discipline and site of care (CMS, 2009a).

4.1.1 The Affordable Care Act’s New Hospice Payment Mandates and Authorizations

The Affordable Care Act requires CMS to collect new hospice data, as discussed above in the Introduction. The legislation did not specify the data to be collected, but rather allows the Secretary to determine what would be appropriate in helping to reform the hospice payment system. In addition to new data reporting requirements, the Affordable Care Act also addresses other Medicare hospice program-related issues through several provisions. Starting in fiscal year (FY) 2014, CMS has the authority to revise the hospice payment rate methodology for routine home care and other services, provided that the revisions are budget-neutral in the initial year of implementation. The Affordable Care Act also requires a productivity adjustment to the hospice annual update for FY 2013 and each subsequent fiscal year, and allows for an additional market basket reduction for FY 2013 through FY 2019 (Section 3401(g) of Affordable Care Act, 2010). CMS is also authorized under section 3140 of the Affordable Care Act to conduct a three year concurrent care demonstration program at up to 15 rural and urban locations to compare cost, access, and quality of hospice concurrent care to current Medicare services for patients with terminal illnesses. The Affordable Care Act also requires CMS to publish hospice quality measures (Section 3004 of Affordable Care Act, 2010), discussed in the following section.

4.1.2 Hospice Quality Measurement, Initiatives and Opportunities for Improvement

Hospice Quality Measurement

Currently, information comparing quality across hospice providers is not publicly available. Over the past decade, there have been a number of initiatives designed to help define hospice quality, including work by the Institute of Medicine (IOM), the Agency for Healthcare Research and Quality (AHRQ), and the National Quality Forum (NQF). Others have sought to assess quality of hospice care through the use of surveys and interviews with patients and families, including NHPCO’s Family Evaluation of Hospice Care (FEHC) and End Results Outcome Measures (EROM), and the National Association for Home Care and Hospice’s patient and family surveys. Hospice quality assessments have limitations however—surveys are voluntary, patient responses may be compromised by declining health and cognitive status, responses of family members may not reflect a patient’s actual
experience, information needed to assess the quality of end-of-life care being delivered is often not captured in a manner that can be used for measurement purposes (i.e. structured data fields in an electronic health record) and there is a tendency for the families that do respond to give only positive ratings (MedPAC, 2010d; Dy et al., 2012).

The measurement of hospice care quality is further complicated by unique, patient population-specific challenges. Caring for hospice patients is unlike caring for any other patient population. As noted by Teno (2005), for most patients who suffer an acute myocardial infarction (AMI), the goal of care is to preserve myocardial function and prevent future AMI. However, in the case of hospice patients the care goal is usually largely different. For example, hospice patients on opiates for pain reduction may have symptom control goals that are based on their preferred level of acceptable pain vs. the opiate’s side effects. This variability in patient preference, though tailored, and patient-centered, makes it difficult to develop quality metrics that are appropriate for all patients (Dosa et al., 2010). Unique to the hospice patient population is also the extreme difficulty of obtaining interviews and information from patients at the end-of-life to evaluate quality and patient perceptions of the quality of care. To address this, the FEHC survey utilizes family members as both proxies for patients post-death and report on the quality of care delivered to them to retrospectively evaluate quality (Teno, 2004).

Although families are considered to be the best proxies for decedents, the quality data captured by the FEHC is still not patient-derived. The FEHC in its voluntary implementation through the National Hospice and Palliative Care Organizations found substantial facility variation in the bereaved family members’ perceptions of quality of care suggesting that the ability of the FEHC to discriminate the quality of hospice programs and potentially provide important information to consumers to select a hospice program may be limited. The FEHC is an NQF endorsed measure.

In 2008, CMS revised the Hospice Conditions of Participation to require that hospices develop, implement and maintain a quality assessment and performance improvement (QAPI) program, which must include the collection of performance data on measurable quality indicators, continuous monitoring of these data, and use of the data to improve quality of care (Federal Register, 2008a). The Conditions of participation do not require that quality data be reported to CMS. Currently, QAPI data are not publicly reported (MedPAC, 2010d). The Affordable Care Act, Section 3004, established a new quality reporting program for hospices. Starting in FY 2014, hospices that fail to meet quality reporting requirements will receive a two percentage point reduction to their market basket update. This statute further provides that “such data shall be submitted in a form and manner, and at a time, specified by the Secretary” (Section 3004 (c) of the Affordable Care Act, 2010).

CMS has finalized hospice quality measures and an implementation approach for this provision in the Hospice Wage Index Final Rule for FY 2012. Additionally, in the Final Rule for the Home Health Prospective Payment System Rate Update for Calendar Year 2013 (77 FR 67134, November 8, 2012), CMS finalized quality reporting requirements for hospices for the FY 2015 payment determination and each subsequent year. In February, 2012 the NQF endorsed multiple measures for palliative and end of life care. CMS has considered several of these measures for future use in the Hospice Quality Reporting Program.

Section 3004 of the ACA also requires public reporting of quality data but does not establish a timeframe for public reporting. The Affordable Care Act also directs CMS to conduct a pilot program to test a value-based purchasing program for hospices no later than January 1, 2016 (Section 10326 of
the Affordable Care Act, 2010). Over the course of the next few years, CMS plans to select a set of quality measures for pilot testing under the value-based purchasing program.

Relative to other federal programs, collection and use of hospice quality measurement is still in its infancy. In addition to the FEHC and other hospice quality surveys, the majority of other tools available to measure hospice quality are designed to retrospectively assess the management of patients’ symptoms at the end-of-life (Stiel et al., 2012). However, there are a lack of instruments and methodologies available to appropriately measure quality, satisfaction and symptom-control for hospice patients and family members in real-time and while patients are still alive. This is because there are many issues related to measuring and burdening this vulnerable population at the end-of-life. Despite these challenges, important work is being conducted to address this gap. Kiely et al. (2012) validated two assessment instruments that can be administered to dementia patients and family members at the end-of-life while patients are still alive: 1) the end-of-life in dementia scale for symptom-management and 2) the end-of-life in dementia scale for satisfaction. Similarly, Mayland et al. (2012) recently developed the “Evaluating Care and Health Outcomes Instrument for the Dying” to measure quality of care at the end of life for hospice patients, specifically in regards to the last few days of life.

**Scan of Hospice Quality Initiatives**

In the private sector, a number of innovative pilot programs have been implemented to address patient barriers to hospice care and improvement in quality of care (Krakauer, 2011). The observed rate at which patients elect hospice is well below what would be expected to appropriately care for advanced illnesses, and significant variation exists in election of hospice by race, age, diagnosis and location (Connor et al., 2007; Emanuel et al., 2002; McCarthy et al., 2003; Keating et al., 2006). Furthermore, it is known that patients report that they would prefer a death in hospice, with tailored palliation and family support, over a death in a hospital (Last Acts, 2002). In an attempt to address these gaps in care, Spettell et al. (2009) implemented a pilot program that provided patients with specialized, palliative care-based case management that also allowed patients to enroll in hospice within 12 months of end-of-life rather than 6 months. This program was found to increase patients’ hospice election by 80%, decrease acute care days and intensive care days by 82% and 88%, respectively, and improve patient and family satisfaction. The results of this study demonstrated how innovation and redesign of hospice care delivery can significantly improve quality and access to needed palliative services for terminally ill patients (Spettell et al., 2009; Krakauer et al., 2009).

Current quality initiatives are also focusing on the “environment” as it pertains to hospice care. Aoun et al. (2012) found that by providing routine home care patients with either a personal alarm device or additional aide hours, patients were able to feel more comfortable and could continue to live independently at home rather than in a long-term care facility. This is advantageous in terms of both cost and patient preference. Environment has also been considered in terms of the in-hospital setting. Brereton et al. (2012) concluded that despite the majority of deaths occurring in hospitals and environment having a profound impact on health, well-being, independence and quality of life, a limited amount of research has been conducted to understand how the physical hospital environment can be altered to improve hospice care for the many patients who die in an in-hospital setting every year. Lastly, recommendations have also been made to apply hospice principles and best practices in nontraditional settings, such as in emergency rooms. In fact, an initiative is currently underway to develop a subspecialty certification for physicians in Emergency Department Hospice and Palliative
Care Medicine to prepare providers caring for patients at the end-of-life who present and die in the emergency room (Lamba & Mosenthal, 2012).

Hospice quality initiatives also span across hospice providers. In February of 2012, the Coalition of Hospices Organized to Investigate Comparative Effectiveness (CHOICE) was established. CHOICE is a new, national network of hospice providers who pool their electronic health record data together and analyze it to answer important clinical and policy-oriented questions. In addition to data sources such as claims and MDS data, CHOICE provides a complimentary data resource that can be used to study implementation results, utilization, and the effect of new therapies and models of healthcare delivery across numerous hospice providers (Casarett et al., 2012).

**Opportunities for Improvement**

To date, there are a number of opportunities described in the literature to improve hospice care as well as access to hospice care for patients who would most benefit from it. The benefits of hospice at the end of life have been well documented. For example, Miller et al. (2012) found that nursing home residents enrolled in hospice had fewer aggressive treatments and lower odds of in-hospital death compared to patients not enrolled in hospice. Despite these advantages, almost one-third of older adults in the U.S. receive care in a skilled nursing facility during the last six months of life, while 1 in 11 of these individuals die in this setting (Aragon et. al., 2012). Thus, significant opportunity exists to improve patient referrals to, and enrollment in, hospice programs. In part, this may be accomplished through the implementation of provider incentives and new models of care delivery (Munn et al., 2012). The timing of hospice enrollment is also considered to represent an opportunity for improvement. Short hospice lengths of stay have raised concern regarding whether patients and families are able to receive and benefit from the broad range of hospice services available to them prior to death. However, short hospice lengths of stay may be unavoidable for approximately one-third of patients. Therefore, systems need to be developed to ensure high quality of care for hospice patients both with long and short lengths of stay (Teno et al., 2012).

Another opportunity for improvement exists in the services provided to caregivers and family members. Bialon and Coke (2012) found that caregivers need more support from hospice providers in terms of education in caregiving, best practices and stress management. Similarly, Barry et al. (2012) found that families may require more support from hospices in terms of bereavement services. Although Barry et al. found that 78% of providers provided bereavement services to family members, only a small percentage of them provided labor intensive (23%) and comprehensive services (27%).

Although interventions and improvement programs have not yet been developed to address disparities in hospice care, evidence of significant differences in the quality of hospice care being delivered to different subpopulations of hospice patients continues to grow. In studying Medicare beneficiaries with heart failure (n=219,275) who died between 2000 and 2008, Unroe et al. (2012) found that non-white patients were more likely to experience an emergency room visit, hospitalization, or intensive care unit stay when enrolled in hospice compared to white patients. Similarly, researchers have documented that among hospices servicing higher proportions of African American patients, family members report more concerns regarding care coordination and the overall quality of hospice care being delivered (Rhodes et al., 2012). In general, minorities groups are also thought to be disadvantaged in both accessing and appropriately using hospice care. Javanovic (2012) found that hospice providers often experience cultural clashes with patients when the hospice providers’ level of cultural competency is weak. Linguistic barriers and a lack of racial and ethnic diversity among
hospice staff are also believed to negatively impact access to, and quality of, hospice care delivered to minority populations.

The role of pharmacists in delivering high quality hospice care to patients has recently been identified as an area of focus (and improvement) for hospices. Polypharmacy for hospice patients is known to be associated with an increase in prescribing inappropriate medication to patients, as well as an increase in adverse drug events, drug-drug interactions, hospitalizations, and costs (Tamura et al., 2012). Across hospice programs pharmacists are responsible for a wide range of clinical, administrative, and dispensing services, but play a critically important role in managing patient symptoms through medication use at the end of life (Latuga et al. 2012). Therefore, there have been calls for the direct integration of pharmacists on interdisciplinary hospice teams to improve patient care. However, pharmacists’ roles vary across hospice facilities and tend to be administrative in hospices that are free-standing, affiliated with a school of pharmacy and are large in terms of patient census (Latuga et al., 2012). Thus, there are a number of opportunities to better define and standardize pharmacists’ roles and responsibilities across providers to ensure high-quality care is being delivered. Similarly, recommendations have also been made for the development of hospice quality measures to address inappropriate prescribing in hospices (Raijmakers et. al., 2013).
5. Findings Related to the Research Questions

5.1 Growth and Change in the Hospice Industry

- What recent trends in hospice utilization are in keeping with the original payment system?
- How effective is the current payment system in promoting access to appropriate care?
- In what ways are Medicare hospice costs exceeding the cost of conventional care?

Over the past decade, hospice access and utilization have increased as evidenced by 1) an increase in the percentage of Medicare decedents served by hospice, 2) an increase in the number of hospice providers, and 3) growing availability of hospice in rural areas. In addition to serving more beneficiaries, hospice lengths of stay and the number of enrollees with non-cancer diagnoses are increasing. Almost all of the increase in hospice providers is accounted for by an increase in for-profit hospices. In the context of payment reform, these trends are relevant because: the current hospice population differs from the population of mostly cancer patients on which the current payment model was based, and the cost of hospice care relative to conventional care varies by length of stay and diagnosis.

5.1.1 Overall Trends in Hospice Enrollment and Utilization

According to statistics compiled by MedPAC for its 2012 Report to the Congress, hospice utilization has increased over the past decade. Between 2000 and 2010, total hospice enrollment increased from 513,000 to 1.16 million beneficiaries. Table 2, below, shows changes in hospice enrollment and utilization between 2000 and 2010. During this period, the percentage of Medicare decedents enrolled in hospice increased from 23% to 44% (MedPAC, 2012). Medicare hospice expenditures more than quadrupled over this time period, rising from $2.9 billion in 2000 to $13 billion in 2010 (MedPAC, 2012). The increased expenditures are due not only to the increased hospice enrollment but also to increases in hospice average length of stay. Among hospice users, the average length of stay (lifetime hospice days) increased from 54 days in 2000 to 86 days in 2010 (MedPAC, 2012).

Table 2: Trends in Hospice Enrollment and Utilization

<table>
<thead>
<tr>
<th></th>
<th>2000</th>
<th>2010</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Medicare hospice enrollment</td>
<td>513,000</td>
<td>1,159,000</td>
</tr>
<tr>
<td>Medicare decedents enrolled in hospice</td>
<td>22.9%</td>
<td>44.0%</td>
</tr>
<tr>
<td>Medicare hospice expenditures</td>
<td>$2.9 billion</td>
<td>$13 billion</td>
</tr>
<tr>
<td>Medicare beneficiaries average total hospice days per lifetime</td>
<td>54 days</td>
<td>86 days</td>
</tr>
<tr>
<td>Medicare beneficiaries median hospice days per lifetime</td>
<td>17 days</td>
<td>18 days</td>
</tr>
</tbody>
</table>

Sources: MedPAC (2012).

5.1.2 Changes in Hospice Provider Characteristics

The total number of hospice providers increased 50% between 2000 and 2009, with the total number of hospices increasing from 2,318 to 3,476 (MedPAC, 2011). Between 2000 and 2009 the number of hospices increased in both urban (62%) and rural (31%) areas (MedPAC, 2011). Hospice growth varied by state between 2000 and 2009, with the number almost doubling in some states (Alabama, Louisiana, Mississippi, South Carolina, Texas and Utah) and declining slightly in other states (Arkansas, Kentucky, Maryland, New York and North Dakota). Fifty percent of all hospices in 2009 were considered medium sized (between 3,500 and 19,999 covered days per year), while 32% were
large hospices (20,000 covered days or more), and small hospices (less than 3,500 covered days per year) made up 18% \((Federal \ Register, 2010)\). Table 3 below provides an overview of hospice providers by location and size. The following table, Table 4, provides an overview of hospice provider affiliation and ownership.

**Table 3: Hospice Provider Location and Size, 2009**

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Number (Percent)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of hospice providers</td>
<td>3,429</td>
</tr>
<tr>
<td>Urban/rural location (^a)</td>
<td></td>
</tr>
<tr>
<td>Urban</td>
<td>2,380 (69%)</td>
</tr>
<tr>
<td>Rural</td>
<td>1,049 (31%)</td>
</tr>
<tr>
<td>Region (^a)</td>
<td></td>
</tr>
<tr>
<td>New England</td>
<td>132 (5.5%)</td>
</tr>
<tr>
<td>Mid-Atlantic</td>
<td>238 (10%)</td>
</tr>
<tr>
<td>South Atlantic</td>
<td>345 (14%)</td>
</tr>
<tr>
<td>East North Central</td>
<td>327 (14%)</td>
</tr>
<tr>
<td>East South Central</td>
<td>176 (7%)</td>
</tr>
<tr>
<td>West North Central</td>
<td>180 (8%)</td>
</tr>
<tr>
<td>West South Central</td>
<td>459 (19%)</td>
</tr>
<tr>
<td>Mountain</td>
<td>222 (9%)</td>
</tr>
<tr>
<td>Pacific/Outlying</td>
<td>301 (13%)</td>
</tr>
<tr>
<td>Size (measured by covered days)</td>
<td></td>
</tr>
<tr>
<td>Small 0–3,499 covered days</td>
<td>611 (18%)</td>
</tr>
<tr>
<td>Medium 3,500–19,999 days</td>
<td>1,715 (50%)</td>
</tr>
<tr>
<td>Large 20,000+</td>
<td>457 (32%)</td>
</tr>
</tbody>
</table>

\(^a\) Data as of February 25, 2010, for hospices with claims filed in FY 2009


**Table 4: Hospice Provider Affiliation and Ownership, 2009 and Change 2000–2009**

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>#</td>
<td>%</td>
<td>#</td>
</tr>
<tr>
<td>Number of hospice providers</td>
<td>2,318</td>
<td>100%</td>
<td>3,476</td>
</tr>
<tr>
<td><strong>Affiliation</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Free-standing</td>
<td>1,188</td>
<td>51%</td>
<td>2,358</td>
</tr>
<tr>
<td>Home health agency</td>
<td>556</td>
<td>24%</td>
<td>569</td>
</tr>
<tr>
<td>Hospital-based</td>
<td>560</td>
<td>24%</td>
<td>528</td>
</tr>
<tr>
<td>Nursing home-based</td>
<td>14</td>
<td>1%</td>
<td>21</td>
</tr>
<tr>
<td><strong>Ownership</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Proprietary</td>
<td>756</td>
<td>33%</td>
<td>1,828</td>
</tr>
<tr>
<td>Non-profit</td>
<td>1,198</td>
<td>52%</td>
<td>1,184</td>
</tr>
<tr>
<td>Government</td>
<td>364</td>
<td>16%</td>
<td>464</td>
</tr>
</tbody>
</table>


The increased supply of hospice providers was driven by large increases in the number of for-profit agencies and freestanding hospices. While the number of non-profit hospices decreased slightly from 2000 to 2009, the number of for-profit hospices rose by 142%, from 756 in 2000 to 1,828 in 2009. In 2009, 53% of hospices were for-profit, while 34% were non-profit, and 13% were government-owned.
(MedPAC, 2011). Freestanding hospices experienced a growth of 98% during this period, increasing from 1,188 hospices in 2000 to 2,358 in 2009. In 2009, 67% of hospices were freestanding, while 17% were affiliated with home health agencies, 16% were hospital-based, and less than 1% were affiliated with nursing homes (Federal Register, 2010).

5.1.3 Variations in Hospice Care Patterns by Ownership Status

An increase in for-profit hospices accounts for most of the overall growth in the number of hospices in the past decade. Between 2000 and 2009, the number of for-profit hospices grew from 756 to 1,828, an increase of 142% (MedPAC, 2011). In 2009, for-profit hospices accounted for 53% of all hospices compared to 33% in 2000 (MedPAC, 2011). While overall profitability in the hospice industry is low, for-profit hospices are more profitable than non-profit hospices (O’Neill et al., 2008). In 2008, the average Medicare margin was 10% for for-profit hospices and only 0.2% for non-profit hospices (MedPAC, 2011). The pattern of substantially higher margins for for-profit hospices has been observed consistently over time, leading to concern that Medicare’s per diem payment system favors for-profit hospices, which have lower costs per patient day than non-profit hospices (Wachterman et al., 2011; MedPAC, 2009). These lower costs may be a result of for-profit hospices being more efficient, because they serve a different type of patient, or because they offer a different level of services than non-profit hospices (MedPAC, 2008). Because of the lack of detailed data on the number and types of visits and services provided to hospice patients, it has not been possible to fully explore whether or not for-profit hospices are more efficient than hospices with other types of ownership. However, researchers have found that in comparison to non-profit hospices, for-profit hospices have a higher proportion of patients with dementia and other non-cancerous diagnoses (Lindrooth & Weisbrod, 2007; Wachterman et al., 2011; Lorenz et al., 2002), who require less skilled care (Cherlin et al., 2010; O’Neill et al., 2008) and have longer average LOS (O’Neil et al., 2008; Lindrooth & Weisbrod, 2007; Wachterman et al., 2011) than patients with cancer. It has also been found that for-profit hospices tend to serve a higher percentage of residents of long-term care and persons who have government insurance (Lorenz et al., 2002). Furthermore, research has found that for-profit hospices provide fewer discretionary or non-core hospice services (Carlson et al., 2004; Jarosek et al., 2009), than non-profit hospices. These findings, though, do not address the impact that these differences have on quality of care and satisfaction among patients and families using hospice (Cherlin et al., 2010; O’Neill et al., 2008).

O’Neill et al. (2008) found that the average LOS for for-profit hospices was 12 days longer than non-profit hospices, and that the financial advantage of for-profit hospices is largely explained by this difference in LOS. Likewise, Lindrooth and Weisbrod (2007) found that, in comparison to patients in religious non-profit hospices, patients in for-profit hospices had significantly longer LOS (a difference of about 14 days) due to differences in the diagnoses and condition of patients admitted. In a study of a nationally representative sample of 4,705 patients discharged from hospice in 2007, Wachterman et al. (2011) found that for-profit hospices had a significantly longer median LOS (20 days vs. 16 days), were more likely to have stays of 365 days or longer (7% vs. 3%), and were less likely to have stays under seven days compared to non-profit hospices (28% vs. 34%). They also found that in comparison to non-profit hospices, for-profit hospices had a significantly higher proportion of patients with dementia (17% vs. 8%) and other non-cancer diagnoses (49% vs. 43%), which were associated with longer LOS and fewer skilled visits per day than patients with cancer diagnoses (Wachterman et al., 2011). Oppositely, in an analysis of all licensed California hospices, Lorenz et al. (2002) found that LOS did not significantly differ between for-profit and non-profit hospices.
hospices. However, as suggested by the authors, this finding may be due to the use of hospice-level aggregate data, which the authors stated was not as accurate as patient-level data. Despite concerns over for-profit hospices having a disproportionate amount of dementia patients and caring for them for a longer period of time compared to non-profits, one large for-profit nursing home chain found that only a small proportion of their dementia patients were still alive within 6 months of their admission date or had been discharged alive (Johnson et al., 2012).

In a study of all Medicare-certified hospices in 2006 from the Medicare Provider of Services (POS) file (n=3,927), Cherlin et al. (2010) found that, while for-profit hospices offer a similar range of professional disciplines as non-profit hospices, they employ a lower proportion of skilled staff. For-profit hospices had significantly fewer clinicians per total full-time equivalents (FTEs), fewer registered nurses per nursing FTEs, and fewer medical social workers per psychosocial FTEs than non-profit hospices (Cherlin et al., 2010). In a study comparing 158 hospices in California in 2003, O’Neill et al. (2008) found that a lower proportion of total nursing visits were provided by registered nurses in for-profit hospices compared to non-profit hospices. In contrast to these findings, Lorenz et al. (2002) found that for-profit hospices delivered more total nursing visits per day than non-profit hospices. However, this difference became insignificant after controlling for patient characteristics.

In a study of 2,080 patients cared for by 422 hospices nationwide using 1998 National Home and Hospice Care Survey data, Carlson et al. (2004) evaluated differences in the provision of services to patients based on ownership status. After adjusting for covariates, for-profit hospice patients received a significantly narrower range of services than non-profit hospice patients. The major difference was attributed to receipt of fewer “noncore” or “more discretionary” services, such as “continuous home care, occupational, intravenous, speech, and physical therapy; durable medical equipment and supplies; respite care; personal care; medications; homemaker/household services; and other high-tech care” (Carlson et al., 2004, p. 433). The relationship between hospice ownership and the range of services offered is highlighted by a study of palliative radiotherapy use among hospices. Palliative radiotherapy is an expensive treatment used to reduce pain and other symptoms related to tumor growth. Hospices may choose to provide this treatment for patients who may benefit from it, but Medicare does not provide additional payments to cover the cost of this service (CMS, 2011b). In a study of 952 freestanding hospices in 2002, Jarosek et al. (2009) demonstrated that non-profit hospices are more than twice as likely to provide palliative radiotherapy as for-profit hospices.

Additionally, McCue and Thompson (2005) found that publicly traded for-profit hospices earned substantially higher profit margins than similarly sized private, for-profit and non-profit hospices. The researchers found that in comparison to large non-profit hospices, large publicly traded hospices served a larger proportion of Medicare patients and offered fewer discretionary services. The smaller publicly traded hospices had longer LOS, a larger proportion of Medicare patients and lower operating expenses than small non-profit hospices. For both large and small hospices, publicly traded for-profit hospices served more patients per day than privately owned for-profit hospices (McCue and Thompson, 2005).

In summary, the findings from the literature discussed above indicate that for-profit hospices have consistently higher profit margins than non-profit and government owned hospices, and that publicly traded for-profit hospices are considerably more profitable than both privately owned for-profit hospices and non-profit hospices. The differences in profitability might possibly be explained by greater efficiency. Medicare’s current per diem payment system, however, provides an incentive for
hospices to maintain lower costs per patient day. Therefore, the higher profitability of for-profit hospices in comparison to non-profit hospices may be attributable to having a higher proportion of patients with non-cancer diagnoses, who tend to have longer LOS and require less skilled care. Lastly, it is important to note the implications of these findings in terms of patient care and hospice quality have not yet been defined. When feasible, the patterns and characteristics described above will need to be cross-walked with quality and/or patient and family satisfaction data to assess whether hospice beneficiaries are being cared for appropriately.

5.1.4 Changes in Hospice Diagnoses and Length of Stay

Diagnosis patterns among Medicare hospice enrollees have been changing, with a growing percentage of patients with non-cancer diagnoses, as shown in Table 4, below. When the hospice benefit began, cancer patients accounted for the largest percentage of hospice admissions (NHPCO, 2011). The percentage of Medicare hospice patients with a primary diagnosis of cancer dropped from 53% in 1998 to 31% in 2008 (CMS, 2009c). Lung cancer was the most common diagnosis for Medicare hospice patients from 1998 until 2006, when it was replaced by non-Alzheimer’s dementia (CMS, 2009c). There have also been notable increases between 1998 and 2008 in neurologically-based diagnoses, such as Alzheimer’s disease and dementia, and non-specific diagnoses, such as “debility, not otherwise specified” and “adult failure to thrive” (CMS, 2009c).

Many of the diagnoses that have experienced a large growth in numbers of hospice users have also shown increases in annual length of stay (LOS). The average LOS of 48 days in 1998 rose to 71 days in 2008, a 48% increase. Table 5 also shows that non-cancer diagnoses have not only experienced a growth in prevalence among the hospice population, but also account for a large increase in hospice LOS. While the average LOS for diagnoses such as chronic kidney disease and cancers remained relatively stable between 1998 and 2008, average LOS increased significantly for most other diagnoses over this time period. The largest increases in LOS were for the non-specific diagnoses (“debility, not otherwise specified,” “adult failure to thrive,” Alzheimer’s disease and non-Alzheimer’s dementia) (CMS, 2009c).

As noted previously, dementia patients have longer LOS and require lower skilled care over this disease trajectory compared to hospice cancer patients. However, it is important to note that these characteristics do not suggest that persons dying from dementia have less important care needs at the end-of-life compared to patients with other diagnoses. These findings should not be interpreted to mean that symptom burden and care needs differ across diagnoses at the end-of-life, but rather that different disease trajectories exist. Despite requiring less skilled care, dementia patients are highly complex and challenging to care for. In fact, it has been well documented that dementia patients have unmet care needs, experience poorer quality of care than patients with other diagnoses, and should receive intensive individualized comfort care (Teno et al., 2011; Mitchell et al., 2004; Mitchell et al., 2009; Lopez & Amella, 2012). Providers are also now calling for the development of new, more accurate prognostic tools specific to the dementia population that can be used to better understand when hospice would be most beneficial for these patients (Johnson et al., 2012; Brown et al., 2012). However, prognostic modeling for hospice patients has proven difficult. Currently available tools are modest at best in identifying patients who are within 6 months of death (Mitchell et al., 2010).
Table 5: Trends in Hospice Enrollment and Length of Stay by Diagnosis

<table>
<thead>
<tr>
<th>Terminal Diagnosis</th>
<th>1998</th>
<th></th>
<th>Avg. LOS (days)</th>
<th>2008</th>
<th></th>
<th>Avg. LOS (days)</th>
<th>1998–2008</th>
<th></th>
<th>Growth in Enrollees</th>
<th>Growth in Avg. LOS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-Alzheimer’s dementia</td>
<td>15,148</td>
<td>3.6%</td>
<td>10</td>
<td>57</td>
<td></td>
<td></td>
<td>113,204</td>
<td>10.8%</td>
<td>1</td>
<td>89</td>
</tr>
<tr>
<td>Debility not otherwise specified</td>
<td>8,534</td>
<td>2.0%</td>
<td>15</td>
<td>51</td>
<td></td>
<td></td>
<td>106,806</td>
<td>10.2%</td>
<td>2</td>
<td>83</td>
</tr>
<tr>
<td>Lung cancer</td>
<td>67,527</td>
<td>16.0%</td>
<td>1</td>
<td>43</td>
<td></td>
<td></td>
<td>95,417</td>
<td>9.1%</td>
<td>3</td>
<td>45</td>
</tr>
<tr>
<td>Heart failure</td>
<td>29,478</td>
<td>7.0%</td>
<td>2</td>
<td>52</td>
<td></td>
<td></td>
<td>89,068</td>
<td>8.5%</td>
<td>4</td>
<td>75</td>
</tr>
<tr>
<td>Non-infectious resp. disease</td>
<td>22,522</td>
<td>5.4%</td>
<td>4</td>
<td>63</td>
<td></td>
<td></td>
<td>72,699</td>
<td>6.9%</td>
<td>5</td>
<td>86</td>
</tr>
<tr>
<td>Failure to thrive a</td>
<td>10,719</td>
<td>1.8%</td>
<td>&gt;20</td>
<td>50</td>
<td></td>
<td></td>
<td>67,790</td>
<td>6.5%</td>
<td>6</td>
<td>82</td>
</tr>
<tr>
<td>Other heart disease</td>
<td>18,294</td>
<td>4.3%</td>
<td>7</td>
<td>57</td>
<td></td>
<td></td>
<td>61,455</td>
<td>5.8%</td>
<td>7</td>
<td>82</td>
</tr>
<tr>
<td>Alzheimer’s disease</td>
<td>12,829</td>
<td>3.0%</td>
<td>12</td>
<td>67</td>
<td></td>
<td></td>
<td>60,488</td>
<td>5.8%</td>
<td>8</td>
<td>105</td>
</tr>
<tr>
<td>CVA/Stroke</td>
<td>22,149</td>
<td>5.3%</td>
<td>5</td>
<td>36</td>
<td></td>
<td></td>
<td>56,986</td>
<td>5.4%</td>
<td>9</td>
<td>53</td>
</tr>
<tr>
<td>Colo-rectal cancer</td>
<td>27,448</td>
<td>6.5%</td>
<td>3</td>
<td>49</td>
<td></td>
<td></td>
<td>33,185</td>
<td>3.2%</td>
<td>10</td>
<td>55</td>
</tr>
<tr>
<td>Blood/lymph cancer</td>
<td>16,645</td>
<td>4.0%</td>
<td>8</td>
<td>37</td>
<td></td>
<td></td>
<td>25,593</td>
<td>2.4%</td>
<td>12</td>
<td>41</td>
</tr>
<tr>
<td>Breast cancer</td>
<td>16,220</td>
<td>3.9%</td>
<td>9</td>
<td>56</td>
<td></td>
<td></td>
<td>22,535</td>
<td>2.1%</td>
<td>15</td>
<td>58</td>
</tr>
<tr>
<td>Prostate cancer</td>
<td>18,885</td>
<td>4.5%</td>
<td>6</td>
<td>53</td>
<td></td>
<td></td>
<td>21,632</td>
<td>2.1%</td>
<td>17</td>
<td>60</td>
</tr>
<tr>
<td>All diagnoses</td>
<td>420,761</td>
<td>100%</td>
<td>48</td>
<td></td>
<td></td>
<td></td>
<td>1,050,705</td>
<td>100%</td>
<td>71</td>
<td></td>
</tr>
</tbody>
</table>

a 1998 numbers for failure to thrive are from 2001, the first year the diagnosis was in the top twenty.

Source: CMS (2009c).
5.1.5 Hospice Care Delivery in Nursing Homes

Hospice Use

Delivery of hospice care in nursing homes has grown consistently since the authorization of hospice care in nursing homes under State Medicaid plans by the Consolidated Omnibus Reconciliation Act (Consolidated Omnibus Reconciliation Act, 1985). In an analysis of nursing home resident assessment records between 1992 and 1996 in five states (n=3,848,114), Miller and Mor (2001) found that 24% of Medicare hospice patients in the five states included in the study resided in a nursing home. Nursing home residents admitted to hospice following nursing home admission represent 78% of hospice patients in the study. More recently, a study of hospice use among nursing home decedents between 1999 and 2006 by Miller et al. (2010a) found that 25% of all Medicare hospice beneficiaries received care in nursing homes in 2006, up from 22% in 1999. Using the National Home and Hospice Care Survey (n=7,288), Stevenson et al. (2007) found similar results: hospice care in institutional settings grew substantially between 1990 and 2000, and that this growth was largely driven by the expansion of hospice care in nursing homes. Miller et al. (2010a) found that the number of nursing home patients receiving hospice care doubled from 101,843 in 1999 to 233,844 in 2006, the proportion of nursing home decedents who used hospice increased from 14% to 33% over the same time period, and that the number of Medicare-certified hospices providing care in nursing homes increased by almost 50%, from 1,850 in 1999 to 2,768 in 2006.

Evidence suggests that the quality of care delivered to nursing home patients enrolled in hospice may be higher than for those patients not enrolled in hospice at the end-of-life. Miller et al. (2002) found that nursing home patients enrolled in hospice had significantly better pain management than patients not enrolled in hospice, while Baer et al. (2000) found that families reported improved symptom control for their loved ones after enrolling in hospice. Teno et al. (2011) also found that bereaved family members of hospice patients with dementia reported higher perceptions of quality of care and dying. Though delivering hospice care in nursing homes provides an opportunity to render high-quality, intensive palliative care to patients, effective use of hospice in nursing homes may still be insufficient (Miller & Mor, 2002). In a study by Parker-Oliver et al. (2003), it was found that patients who would have benefited from palliative care often failed to receive it in nursing homes. It has been suggested that to most effectively improve hospice care quality and access in nursing home facilities, policy-level interventions such as educational initiatives and alteration of governmental policies to promote nursing home and hospice collaboration may be needed (Miller & Mor, 2002; Parker-Oliver, 2003).

Accordingly, hospice use in nursing homes has been shown to be influenced by changes in governmental reimbursement policies. Miller et al. (2011) found that a $10 increase in Medicaid reimbursement rate resulted in a significant increase in hospice use in urban nursing homes (0.41%) and a significant decrease in use in rural nursing homes (0.37%). This analysis was conducted on a longitudinal dataset of 74,090 facility year observations across 13,111 freestanding nursing homes from 1999–2004. Besides demonstrating the relationship between hospice use and changes in governmental reimbursement policies in nursing homes, this study also illustrated the differential impact of changes in governmental reimbursement rates on urban and rural nursing home utilization.

Length of Stay

Some studies have noted a trend in increased length of stay for hospice patients residing in a nursing home. MedPAC estimated that in 2005, 21% of hospice recipients in nursing homes were enrolled in
hospice for at least six months, while only 12% of patients in other settings had hospice stays beyond six months (MedPAC, 2009). Miller et al. (2010a) found that the mean length of stay for nursing home decedents who used hospice care doubled from 46 to 93 days between 1999 and 2006. The researchers suggested that this was driven by a high proportion of long stays, observing that the proportion of stays longer than 180 days increased from 7% in 1999 to 16% in 2006. Conversely, Stevenson et al. (2007) found that institutionalized hospice users were more likely to be enrolled in hospice care for one week or less compared to hospice users in the home setting (42% vs. 22%).

Huskamp et al. (2010b) sought to better understand the characteristics of nursing home patients associated with both short and long hospice stays. Using data between 2001 and 2008 from a large regional hospice provider (n=1,209), the researchers found that facility characteristics (including the quality of the nursing home) were not statistically significant predictors of long stays (greater than 180 days), but the probability of a very short stay (three days or less) increased with the nursing home’s nurse staffing ratio. The authors speculate that nursing homes with high staffing levels may have the necessary staff to manage end-of-life care until the final days of life, whereas nursing homes with lower staffing ratios may refer patients to hospice relatively earlier to help handle the burden of end-of-life care. Although the authors did not find that the share of residents with Medicaid coverage significantly affected the probability of having a long stay, the probability of a short stay decreased with a greater share of Medicaid residents at the facility. The researchers also found that patients with a terminal diagnosis of Alzheimer’s disease or dementia were more likely to have a long stay and less likely to have a very short stay compared to residents with other terminal diagnoses.

Visit Patterns
Researchers have also assessed visit patterns to better understand the provision of hospice care in nursing homes. Using data from longer stay patients (12–24 weeks of care) at a large for-profit provider, Gruneir et al. (2006) found that hospice visit patterns at nursing homes were similar to those observed for all hospice patients: the most visits and the most expensive visits occurred at the beginning and end of the hospice stay. All types of staff except aides made the most visits in the first and final days of hospice enrollment. Aides had the least activity at the beginning of the stay and relatively stable activity across the middle and final periods of care. The study found that visit rates were similar across all diagnostic groups until the final week of life, when cancer patients received more visits compared to other diagnostic groups (Gruneir et al., 2006).

Patient Characteristics
Stevenson et al. (2007) noted important differences between hospice users in institutional versus home settings. Specifically, they found that hospice users in institutional settings were older, more likely to be female, unmarried, dually eligible, and have a terminal condition other than cancer. Research also indicates that nursing home decedents who receive hospice services during their nursing home stay have fewer hospitalizations and better outcomes with respect to pain management compared to non-hospice nursing home decedents (Miller et al., 2000).

Within the nursing home population, research suggests that hospice use varies by the patient’s terminal diagnosis. Miller et al. (2010b) found that hospice use nearly tripled from 1999 to 2006 among nursing home decedents with mild-to-moderate dementia (13% to 38%) and advanced dementia (15% to 43%). This increased use was accompanied by an increase in mean length of hospice stay for advanced dementia decedents, from 46.1 days in 1999 to 118.2 days in 2006. The researchers also found that patients in both dementia diagnosis groups with an additional diagnosis of
cancer or cardiovascular disease were more likely to access hospice, and the authors suggested that the diagnosis of cancer may have driven the enrollment of patients with dementia (Miller et al., 2010b).

Expenditures
Length of nursing home stay, length of hospice stay, and diagnoses are all related to Medicare expenditures. In a study of one urban, non-profit hospice (n=1,209), Huskamp et al. (2008) examined the cost differences associated with providing hospice care in institutional versus other settings. The researchers found that for the 15% of the sample (n=176) who resided in a nursing home, the total hospice cost per patient (after controlling for length of hospice stay) was 37% lower than costs for patients in other care settings. The researchers also noted that the most important driver of average total cost per day was the duration of stay. The authors speculated that lower costs for hospice care in a nursing home may be attributed to potential overlap of services between the hospice and nursing home and lower travel costs per patient if multiple patients are in the same nursing home (Huskamp et al., 2008). In a study of government expenditures on nursing home patients (n=5,774), Miller et al. (2004) found that overall mean expenditures for the last month of life were significantly less for residents who received hospice care in comparison to those who did not. This reduction of expenditures, however, was not consistent across patients with long and short stays. For short stay nursing home residents who elected hospice, mean government expenditures in the last six months and the last month of life were significantly less than for short stay residents who had not elected hospice. On the other hand, long stay residents who elected hospice had significantly higher mean six month government expenditures than their counterparts who did not elect hospice care, and there was no significant difference in mean expenditure for the last month of life between long stay nursing home residents based on their hospice election. In another study comparing nursing home patients who did and did not receive hospice care, Gozalo et al. (2008) also found that hospice enrollment decreased the last month of Medicare and Medicaid expenditures for patients overall by 6%, but that this finding differed depending on the length of stay and diagnosis. The researchers found that among short stay nursing home residents, hospice enrollment resulted in overall savings of 22%, and savings were relatively uniform across diagnoses. For long stay residents, however, the cost implications were more mixed: for patients with a cancer diagnosis, there was a cost savings of 9%, costs were neutral for dementia patients, and there was nearly a 14% increase in costs for patients without a diagnosis of cancer or dementia. The researchers also found that for short stay residents, the reduced Medicare expenditures were offset to some extent by a modest increase in Medicaid expenditures.

Goldfeld et al. (2011) found that among a sample of nursing home decedents with advanced dementia in Massachusetts (n=323), mean Medicare expenditures increased on average by 65% in each of the last four 90-day periods before death. Although only 22% of the study sample received hospice services, hospice care accounted for the largest proportion of Medicare expenditures (46%) in this group.

5.1.6 Hospice Utilization and Managed Care
Hospice enrollment is consistently higher among Medicare managed care (MMC) enrollees than those in FFS (MedPAC, 2011; McCarthy et al., 2003; Riley & Herboldsheimer, 2001; Virnig et al., 2001). In 2002, 31% of MMC decedents used hospice care compared to 22% of Medicare FFS decedents (MedPAC, 2010d). These differences were smaller in 2009, but hospice enrollment
remained higher among those in managed care, with 46% of managed care decedents enrolled in hospice compared to 41% of FFS decedents (MedPAC, 2011).

Medicare beneficiaries can choose to receive their coverage through a MMC plan. Private insurance companies approved of by Medicare offer MMC coverage as either a Health Maintenance Organizations (HMOs) or Preferred Provider Organizations (PPOs), and provide both Part A and Part B coverage and sometimes additional coverage as well (CMS, 2011b). MMC organizations receive a fixed payment, known as a capitated rate, from CMS for each beneficiary regardless of the services provided. This means that the MMC plan assumes the financial risk for the beneficiary, and can lose money if the cost of the services provided exceeds the capitated rate (Legal Action of Wisconsin, 2009). Likewise, the plan earns profits if services can be provided for less than the capitated rate.

When a beneficiary with MMC coverage enrolls in hospice, however, Fee-For-Service (FFS) Medicare takes over payment for the patient’s hospice and non-hospice care (CMS, 2010c), and the managed care organization is no longer financially liable for the Medicare covered services the patient receives (MedPAC, 2006). Since Medicare’s capitated payment to MMC plans is not adjusted for end-of-life care, and medical expenses in the last months of life tend to be very high, MMC plans typically lose money when covering patients who are not on hospice during this period (Riley & Herboldsheimer, 2001). Therefore, the current hospice payment method creates a financial incentive for MMC plans to encourage dying patients to elect hospice care (Riley & Herboldsheimer, 2001).

Two studies found that MMC patients had statistically longer LOS and different utilization patterns than FFS patients:

- In a study of Medicare cancer patients, aged 66 and older who died between 1988 and 1998 (n=260,000) by McCarthy et al. (2003), MMC patients had a significantly longer median length of stay than FFS patients (32 days vs. 25 days), were significantly more likely than FFS patients to use hospice for at least 2 months prior to death (29% vs. 23%), were significantly less likely than FFS patients to enroll in hospice within seven days of death (19% vs. 23%), and were significantly more likely than FFS patients to have hospice stays of more than 180 days (8% vs. 6%).
- In a study of Medicare beneficiaries 65 and older, who died in one of 100 counties with the largest number of deaths in the managed care system (n=550,325), Virnig et al. (2001) found that the overall median LOS was significantly longer for MMC patients than FFS patients (24 vs. 21 days), seven day mortality was significantly lower for MCC patients than FFS patients (25% vs. 27%) and 180 day survival was significantly higher for MMC patients than FFS patients (13% vs. 12%), although actual differences observed were small.
- Riley and Herboldsheimer (2001), however, found no significant differences in hospice LOS between MMC and FFS patients after controlling for covariates. Their study was of Medicare beneficiaries who were in MMC (n=21,330) or FFS (n=88,501) and died in 1998.

The Virnig et al. (2001) study found that the distribution of diagnoses of hospice users in MMC and FFS were similar, while Riley and Herboldsheimer (2001) found that there were more patients with cancer in MMC than FFS, which they suggested might explain why more MMC patients enroll in hospice.

Riley and Herboldsheimer (2001) noted that while there is a financial incentive for MMC plans to encourage their members to choose hospice for end-of-life care, there were also other explanations for
why MMC patients were more likely than FFS patients to enroll in hospice: patients who chose MMC may also be more likely to have chosen hospice care, perhaps because they are more receptive to care management; the higher rates of cancer-related deaths among MMC enrollees increases demand for hospice care regardless of MMC status; and MMC plans have better case management and may be better able to identify patients who would benefit from hospice care. McCarthy et al. (2003) found no evidence to suggest that managed care organizations enrolled patients in hospice care inappropriately. In fact, they found a more pronounced association between MMC and hospice use for cancer patients who are the most clinically appropriate for hospice care (i.e., those with stage IV or metastatic cancers), which they suggested may be because managed care plans are more successful at encouraging hospice care for patients dying of cancer. MMC plans are also required by CMS to notify their enrollees annually about the option of hospice, and to identify approved hospices in their service area, so MMC patients may be more aware of hospice options than FFS patients (CMS, 2010a).

Virnig et al. (2001) suggested that the differences in hospice enrollment between MMC and FFS may be due to underuse in the FFS system rather than overuse in MMC. It should be noted that all of these studies compared patients who died in the late 1990s, before the large increases in hospice utilization were observed between 2000 and 2009.

In summary of the literature discussed above, hospice enrollment is consistently higher among beneficiaries with MMC than FFS coverage, and this may be at least in part due to the financial incentive created by capitated payments for MMC plans to enroll patients into hospice for costly end-of-life care. However, evidence does not indicate that MMC plans are inappropriately enrolling patients into hospice, and there are other explanations for why MMC enrollees may be more likely to receive hospice care, including better case management.

5.1.7 Access and Variations in Hospice Utilization by Race/Ethnicity

While hospice utilization has increased substantially over the past decade among minority populations (MedPAC, 2011), continuing an earlier trend that was documented by Han et al. (2006), racial and ethnic disparities in hospice use persist. In 2009, 44% of white Medicare decedents used hospice, compared to 35% of Hispanics, 33% of African Americans, 30% of Native North Americans, and 26% of Asians (MedPAC, 2011). A number of prior studies have examined racial disparities in hospice utilization.

A study by Givens et al. (2010) which used a 2001 national sample of 98,258 Medicare beneficiaries with congestive heart failure (CHF), found that after adjusting for individual and market factors, African American and Hispanic patients used hospice less often than non-Hispanic whites. In studying Medicare beneficiaries with heart failure (n=219,275) who died between 2000 and 2008, Unroe et al. (2012) also found that non-white patients were less likely to enroll in hospice and more likely to disenroll once in hospice. Connor et al. (2008) examined the differences in hospice utilization between African American and white elderly decedents who died in 2002 (n=1,811,720). This study found that whites were more likely to have used hospice in the year before their death than African Americans (29% vs. 22%) and that this pattern was consistent across almost all conditions, and in 31 of 40 states. Interestingly, the study found that states with higher hospice utilization rates overall had less disparity in hospice use between African Americans and whites. Han et al. (2006) found that, between 1992 and 2000 hospice use doubled for whites and nearly quadrupled for African Americans.
Some studies found that differences in utilization rates persisted even after adjustment for socio-demographic, clinical conditions, and other factors (Ngo-Metzger et al., 2008; Givens et al., 2010). Several studies, however, have reached different conclusions about racial disparities in hospice utilization, at least for certain patient groups:

- Greiner et al. (2003) found that differences in hospice use are not independent of access to care or income for a study population that consisted of 11,291 people age 55 and older who died of non-traumatic causes in 1993. The study found that there was no significant difference in hospice utilization between African Americans and whites after adjusting for socio-economic factors.
- Kwak et al. (2008) found that while overall hospice utilization rates were lower for African Americans, there was no difference among patients who died of cancer. This study examined a cohort of dual-eligible nursing home residents in Florida (N=30,765) who died between 2000 and 2002.
- Lepore et al. (2010) compared hospice use among Medicare nursing home residents who died in 2006 (n=288,202). Overall, African Americans were less likely to use hospice than whites (35% vs. 39%). Among the subset of patients with do-not-resuscitate orders, however, hospice utilization was higher for African Americans than for whites.
- Johnson et al. (2011) found that African Americans who used hospice services were significantly more likely to have been admitted after a hospital stay than whites. This study examined patients of a national hospice provider, living at home, who died between 2000 and 2003.
- Zheng et al. (2011) found that among New York state long-term nursing home residents (n=49,048) who died between 2005 and 2007, race did not significantly predict hospice use. However, living in facilities with 10% more African-Americans was found to significantly decrease the odds of hospice use by patients.
- Park et al. (2012) found that minority patients, including African-Americans and Hispanics, experienced significantly longer lengths of stay compared to white patients. This study was conducted on a cohort of 16,323 patients who received hospice care in central Florida from 2002 to 2006.

The differences in hospice use across racial and ethnic groups are not fully understood. A systematic review of articles related to African American use of hospice care identified the following barriers to use for this population: conflicting values with hospice philosophy, lack of information about hospice care, concerns about burdening family members, financial concerns, mistrust of the healthcare system, and an expectation that hospices employees would not be minorities (Washington et al., 2008). Yancu et al. (2010) interviewed adults in 11 predominantly African American churches in North Carolina (n=314). Barriers to hospice use identified by this study included a belief that using hospice means giving up hope; a concern that hospice care is too expensive; and a reported preference to care for a loved one at home, indicating a lack of adequate information about hospice. In a study of cancer patients with a life expectancy of six or less months to live (n=283), Fishman et al. (2009) found that African Americans are more likely than whites to desire aggressive cancer treatment.

It is also important to note that across races and ethnicities, individuals with disabilities are also faced with barriers to hospice care. In a recent systematic review of patients with intellectual disabilities, Friedman et al. (2012) discuss the unique challenges of delivering hospice care to the disabled,
including the need for condition-specific training for hospice staff and the development of specialized pathways and referral patterns for care access.

5.1.8 Hospice Access in Urban and Rural Areas

As of 2009, about 70% of hospices were located in urban areas (Federal Register, 2010), and research shows that there were differences in access to hospice based on the population density of a geographic area. Virnig et al. (2006) used Medicare enrollment and hospice files from 2000–2002 to examine the extent to which Medicare beneficiaries had access to hospice care. The study found that, while the vast majority of Medicare beneficiaries had one or more hospices in their geographic location, beneficiaries in rural areas were less likely to have access. Of those in metropolitan areas, less than 0.1% of Medicare beneficiary deaths occurred in areas not served by hospice, compared to 2% in rural areas adjacent to urban areas, and 9% in rural areas not adjacent to an urban area. Carlson et al. (2010a) found that an estimated 88% of the US population live within 30 minutes of a hospice while 98% live within 60 minutes of a hospice provider. The study estimated that there are approximately 6 million people that live in communities that are more than 60 minutes from a hospice.

Both the number of hospices and the number of Medicare decedents using hospice increased in both urban and rural areas between 2000 and 2009 (MedPAC, 2011). Between 2000 and 2009, hospice use increased from 29% to 44% in urban counties, from 19% to 38% in rural counties adjacent to urban counties, from 17% to 34% in rural counties not adjacent to urban ones (MedPAC, 2011). The average annual percentage increase in hospice utilization was larger in rural areas (2.1% for adjacent rural counties and 1.9 for nonadjacent rural counties) than for urban areas (1.5%). In the least densely populated rural counties (those with a population of less than 2,500), hospice use increased from 14% to 31% among Medicare decedents. These numbers indicate that while patients in urban areas continue to have better access to hospice care than rural patients, access is improving for Medicare beneficiaries in rural areas.

Medicare’s current payment system is believed to be a factor limiting access to hospice care in rural settings. Medicare hospice payments are adjusted for location based on local nursing wage rates, which results in substantially higher payments for urban providers compared to rural. Medicare payments are also not adjusted for travel distances, which are thought to be longer and result in increased costs for rural providers (MedPAC, 2001). Due to substantially reduced Medicare payments compared to urban hospice providers, rural hospice providers are believed to be negatively impacted in terms of their ability to maintain staff, remain capitalized and overcome pressures affecting the hospice industry (Virnig et al., 2004, 2006). However, in a study by O’Neill et al. (2009) of 172 hospice providers in California, this notion was not supported. O’Neill et al. (2009) found that profit per patient-day did not significantly differ between urban and rural hospices, despite rural providers receiving reduced Medicare payments. O’Neill et al.’s findings strongly suggest the need to further investigate differences in access, cost and performance between rural and urban hospices, especially when attempting to understand the impact of potential payment reforms on rural vs. urban hospices.

Access to hospice care in rural settings is also believed to be negatively affected by the inability of providers and healthcare facilities to refer eligible patients to hospice programs. Constrained by physician shortages and high staff turnover, healthcare providers are challenged with not only communicating the intent and potential benefit of hospice to terminally ill patients, but also creating meaningful relationships with surrounding hospices to adequately connect patients with hospice
programs. This notion is supported by a study by Temkin-Greener et al. (2012) who found that compared to residents of urban nursing home facilities, patients residing in rural facilities were less likely to enroll in hospice and more likely to experience an in-hospital death.

Although unrelated to rural or urban status, other barriers to hospice access exist in the form of hospice-specific enrollment policies that are designed to restrict access to care for patients with diagnoses and conditions associated with high cost medical care, including chemotherapy and total parental nutrition. Out of 591 hospices surveyed across the U.S. in 2008 and 2009, 78% were found to have at least one restrictive enrollment policy potentially limiting access to hospice care for high cost patients (Carlson et al., 2012). On average, 2.3 restrictive enrollment policies per hospice were observed. In response to these findings, the authors of this study requested that CMS consider implementing a higher per diem reimbursement payment for patients with complex and expensive healthcare needs to encourage providers to remove restrictive enrollment policies.

5.1.9 Impact of Hospice Utilization on Medicare Costs

Several studies have examined the impact of hospice utilization on Medicare costs. The mixed conclusions from these studies are described below.

- Emanuel et al. (2002) examined Medicare beneficiaries (aged 66 and older) who died in 1996 in Massachusetts (N=37,933) and California (N=27,685). In the last year of life, costs were not significantly lower for hospice users, except for patients with cancer. In the final year of life, significant savings were observed for patients who used hospice and had a cancer diagnosis (with a mean of $4,424 of savings among hospice enrollees in Massachusetts and $6,959 in California).

- The findings from Campbell et al. (2004) were similar. This study compared Medicare expenditures between hospice users and non-hospice users for the last year of life, using a sample of all decedents from the Medicare 5% sample who were 67 years old or older, had FFS coverage and died between 1996 and 1999 (n=245,326). Adjusted mean expenditures were 4% ($2,579) higher overall among hospice users versus non-users. Among cancer patients, however, expenditures were 1% less among hospice users. The study found that hospice related savings decreased and relative costs increased with increasing age.

- In a study of Medicare beneficiaries (n=16,613) who died with heart failure, Blecker et al. (2011) found that medical expenditures were higher for decedents with hospice care compared to those without ($34,067 vs. $31,793). Although Blecker et al. did not observe a reduction in expenditures for decedents with hospice care; they found that hospice use was associated with a significantly reduced number of hospitalizations, ICU days and procedures. This led the researchers to conclude that expenditures related to hospice care itself may negate any cost savings associated with reducing intensive medical care for heart failure patients.

- A case-control study by Pyenson et al. (2004) examined cost differences between Medicare patients who did (cases) and did not (controls) elect to receive hospice benefits. The mean Medicare costs were lower for patients enrolled in hospice care for all diagnoses but prostate cancer and stroke, and the cost differences were significant for patients with chronic heart failure, liver and pancreatic cancer. The study found that the lower cost for patients receiving hospice care was not due to shorter survival time, since patients with hospice care had longer mean and median time to death than their matched non-hospice controls.
Taylor et al. (2007) estimated large savings to Medicare associated with hospice utilization. Using a retrospective study of Medicare decedents (aged 67 and older) who died between 1993 and 2003, the study compared Medicare expenditures between 1,819 hospice users and 3,638 matched controls that did not use hospice but were otherwise similar. Medicare expenditures were compared from the date of hospice entry for cases until the date of death, such that the expenditures for the hospice user were compared to the expenditures during the same number of days preceding death for the two matched controls. The study found that hospice use saved Medicare approximately $2,300 per beneficiary (average Medicare expenditures were $7,318 for hospice users compared to $9,627 for controls, p<0.001). The maximum reduction in Medicare savings per user were largest (approximately $7000) for those with a cancer-related primary diagnosis for whom hospice care was provided for 58 to 103 days prior to death. Importantly, total costs between hospice users and non-hospice users did not differ significantly when the researchers compared the entire last year of life, suggesting that failure by other studies to account for the length of hospice use may mask cost differences that occur near death. This may explain the differences in the magnitude of savings estimates reported across studies. Taylor et al. (2007) also found that extremely long hospice LOS resulted in negative savings (increased Medicare cost) for both cancer and non-cancer patients. However, because they found that one fourth of patients used hospice for five days or less prior to death and less than 7% used hospice for more than 180 days, the researchers believe maximum Medicare savings could be achieved by focusing efforts on increasing the length of short stays rather than shortening long ones.

When comparing hospice patients to matched non-hospice controls, Kelley et al. (2013) found that beneficiaries enrolled in hospice were associated with reduced costs and lower rates of hospital utilization and in-hospital death compared to controls. Interestingly, this effect was observed across a variety of lengths of stay, but seemed to grow with shorter enrollment periods. For example, a cost savings of $2,561 was observed for hospice patients with an enrollment period of 53–105 days compared to controls, while cost savings of $2,650, $5,040 and $6,430 were observed for hospice patients with 1–7, 8–14, and 15–30 day enrollment periods compared to controls, respectively. This analysis was conducted on 3,069 beneficiaries using Medicare claims and 2002–2008 Health and Retirement Study decedents data. This study did not examine Medicare cost savings among beneficiaries with hospice LOS in excess of 105 days.

Although not examining Medicare beneficiaries specifically, Weckmann et al. (2012) found that enrollment in hospice was associated with significantly reduced total costs and hospital length of stay for patients. This study was conducted on 209 adult patients who experienced a nontraumatic death and who had a hospital admission up to 12 months before their death at an academic medical center. Weckmann et al. found that patients who enrolled in hospice during their terminal admission had substantially decreased average total costs ($4,963; n=7) compared to those patients who did not enroll in hospice ($52,219; n=202).³

³ Sample size and significant heterogeneity are of primary concern with this study and should be considered when interpreting its results.
5.1.10 Summary: Utilization, Access to Care and Impact on Medicare Costs

In summary, trends in hospice utilization indicate that hospice access and utilization are increasing as evidenced by enrollment of an increasing percentage of Medicare decedents prior to death across multiple diagnoses, an increasing number of hospice providers, and increasing availability of hospice in rural areas. While hospice usage has increased substantially over the past decade for all racial and ethnic groups, racial and ethnic differences in hospice use persist. The overall increase in hospice utilization remains consistent with the original intent of the hospice benefit, to provide an alternative in end-of-life care for terminally ill patients. However, over the past decade, there have been considerable changes in both hospice provider and hospice patient characteristics. For-profit hospices account for almost all of the increase in hospice providers over the past decade. Non-cancer diagnoses have experienced a growth in prevalence among the hospice population, and account for a large increase in hospice length of stay. With regard to comparing the cost of hospice care to the cost of conventional care, while findings are mixed, some research indicates that use of hospice care may generate savings to Medicare compared to conventional care, especially for patients with cancer diagnoses and with moderate lengths of stay. However, trends towards a growing percentage of hospice care for patients with non-cancer diagnoses may be leading to a reduction in any cost savings that might exist, attributable to the provision of hospice care.

5.2 Aligning Reimbursement with Resource Use

- Under what circumstances does the hospice payment system accurately reimburse providers for the reasonable and necessary cost of care?
- What are the effects of patient characteristics, site of service and other factors on the relationship between cost and reimbursement?
  - How should a reformed payment system take these factors into account?

The most comprehensive analyses comparing hospice payments to actual hospice costs are contained in a 2004 GAO report and MedPAC reports from 2006, 2008, 2009, 2010, 2011 and 2012. Results of these reports are presented below. These studies found that while payments are generally adequate, the current hospice payment methodology does not accurately reflect actual care delivery. The 2011 MedPAC report also presents an overview of the growing requirements for new data submissions from hospice facilities as well as the first linkages between quality and payment. These new initiatives are expected to serve as the basis for consideration of broader long-term policy requirements between payment and quality for Medicare hospice.

5.2.1 General Accountability Office Report 2004

Following implementation of the Medicare hospice benefit in 1983, neither the payment methodology nor the payment rates for hospices had been evaluated until the Medicare, Medicaid, and SCHIP Balanced Budget Refinement Act of 1999 (BBRA) directed the GAO to study the feasibility and advisability of updating Medicare’s payment rates for hospice care (Government Accountability Office [GAO], 2004).

The 2004 GAO report compared hospices’ costs to Medicare payment rates and attempted to evaluate the appropriateness of the per diem payment methodology using 2000 and 2001 Medicare hospice cost reports for freestanding hospices (GAO, 2004). To analyze the types of visits provided, 2002 proprietary data on patient visits, collected by a large, for-profit hospice with multiple freestanding
facilities, were used because Medicare hospice cost reports and claims did not contain visit-level data at the time of the investigation.

The GAO found that unadjusted per diem payment rates across the four payment categories (i.e., routine home care, continuous home care, general inpatient care, and inpatient respite care) were approximately 8% higher than estimated average per diem costs in 2000, and more than 10% higher in 2001. The home care ("home care" consisted of both the routine home care and continuous home care payment categories due to aggregate reporting on cost reports) per diem payment rate was nearly 10% higher than average home care per diem costs in 2000, and more than 12% higher in 2001. In both years, the general inpatient care payment rate was approximately 7% higher than average general inpatient care per diem costs. In contrast, the inpatient respite care payment rate was approximately 53% lower than average per diem costs in 2000, and 61% lower in 2001. The disparity between payment and costs for inpatient respite care was attributed to the additional cost of paying the inpatient facility.

For each payment category in both years, average per diem costs were more for small hospices (defined as those in the lowest quartile in terms of total days of care provided) than for larger hospices. In 2001, average per diem costs for small hospices were more than 15% higher than for medium-sized hospices and almost 8% higher than costs of large hospices. The cost disparities by hospice size were greatest for inpatient respite and general inpatient levels of care. Because small freestanding hospices were more likely than medium or large hospices to be located in rural areas, they tend to receive lower Medicare payments because the wage index adjustment generally reduces the payments for providers in rural areas. The combination of higher per diem costs and likely lower payments from Medicare places smaller hospices at a financial disadvantage.

The GAO found that service delivery patterns changed considerably between when the payment system was first devised in 1983 and 2000. During this period, the proportion of routine home care costs attributable to nursing, social services, pharmaceuticals, and medical equipment increased, while the proportion attributable to home health aide services, supplies, and outpatient services decreased. This pattern was observed across hospices of all sizes and locations, suggesting that the services delivered or the resources necessary for those services have changed over time. Medication costs were a major source of increased costs to providers, increasing from 3% of routine home care costs in 1983 to 15% in 2000.

The GAO’s analysis of 2002 patient-specific visit data showed that hospice visits tend to be concentrated at the beginning and end of hospice stays. This results in a U-shaped cost model, with the costs of care being higher at both the beginning and end of a hospice stay. Their analyses showed that the average number of visits per day was higher for patients with a length of stay of two weeks or less compared to patients with a longer length of stay. Providers that were interviewed for the study explained that at the beginning of a hospice stay, intensive symptom management often necessitates more visits. However, as symptoms stabilize, visit frequency decreases until more resources are again needed at the very end-of-life when symptom management and psychosocial needs are high.

The GAO report also identified provider concerns about some of the policy requirements for particular payment categories that may distort service use patterns. For example, there is a requirement that a minimum of 8 hours of care, counted from midnight of one day until midnight of the next, must be furnished to qualify for the continuous home care rate. Some providers expressed concern about billing for patients who die in less than eight hours or for whom the eight hours of care...
is provided over two calendar days. The GAO’s analysis, though, found that the mean hours of service for a CHC day was 18 hours based on 2001 Medicare claims and 20 hours based on 2002 patient-specific data from a large freestanding facility, suggesting that instances of continuous care hours that fall just beneath the 8 hour threshold do not occur often.

Hospice industry officials also stated that the statutory requirement that respite care be provided in an inpatient setting might hinder its use. They noted that though respite is important for primary caregivers, some primary caregivers may not take respite to avoid moving the patient to a facility. Few of the hospices that GAO spoke with provided home respite care for extended periods. A major reason is that the costs of providing such care were higher than the routine home care payment rate, which is the payment category used to bill for respite services.

The GAO report concluded that there were “several indications” that hospice payments may not be appropriately distributed across days of care or provider type, given the changes in type of care provided during a hospice stay that had occurred since implementation of Medicare’s hospice benefit. Because patient-specific data on hospice visits and services were not available from Medicare data, the GAO used data from a single large, for-profit hospice, meaning their results may not be generalizable to all Medicare hospice providers. However, their analyses suggested that overall Medicare payment rates were higher than estimated costs, except for inpatient respite care. The GAO recommended that CMS collect comprehensive, patient-specific data on the utilization and cost of hospice visits and services, and to use these data to determine whether the hospice payment methodology and payment categories need modifications, including any special adjustments for small providers.

5.2.2 MedPAC Report June 2006

Growth of the benefit and changes in the hospice population led MedPAC to evaluate the hospice payment system to assess whether it should be modified to improve the accuracy of hospice payment. MedPAC contracted with RAND to conduct analyses using Medicare patients served by one large, multi-state, for-profit hospice chain (MedPAC, 2006). The data used by the study included detailed information not available from Medicare administrative records and contained information for 68,725 Medicare patients admitted in 2002 and 2003 (this represented approximately 6% of the total Medicare hospice population during the time period examined). The records contained primary International Classification of Diseases, Ninth Revision, Clinical Modification (ICD–9–CM) diagnosis codes, race/ethnicity, marital status, age, whether care was received in a nursing home, discharge status, and location. Individual ICD–9–CM codes were aggregated into nine cancer and seven non-cancer diagnostic categories that were clinically similar and expected to have similar resource use. Resource use was measured by the number of visits received and the labor costs associated with those visits. Visit labor costs were estimated using the number and length of visits and disciplines of the staff involved. These data were merged with Bureau of Labor Statistics (BLS) data on average hourly wages of each discipline and adjusted for geographic location using the Medicare wage index. RAND then estimated regression models to determine which variables were the strongest predictors of hospice resource use, which was defined as number of visits and visit labor costs.

RAND evaluated the ability of case-mix adjustors to improve the predictive accuracy of the payment system. They found little variation in resource use (number of visits and visit labor costs) within each of the four types of care (routine home care, continuous home care, inpatient respite care and general
inpatient care). As a result, the number of visits in a hospice episode was largely a function of the number of days of care by type of day. Using ordinary least squares regressions, RAND found that approximately 90% of the variation in resource use could be explained by the number of days for each type of care. These findings suggest that hospice patients have similar care needs regardless of diagnoses and patient characteristics. It may also be a function of the practice patterns of the chain that provided data for the study.

Although diagnosis and other patient characteristics were statistically significant predictors of both resource measures, adding these covariates to a model that contains days of care by type actually did not improve the ability to predict variation in resource use associated with a hospice episode.

Similar to the GAO’s findings discussed above, RAND’s analysis also found that the beginning and end of hospice stays (i.e., first three and last three days of the stays) are more resource intensive than the middle days. The authors noted that with higher costs associated with the beginning and end of stays, a constant per diem rate may result in providers seeking patients with a longer stay.

A major limitation of the findings was that data were from a single chain, and therefore are likely not generalizable to all Medicare hospice patients (for example, the chain may have more homogenous practice patterns than a randomly selected sample of Medicare hospice providers). Another limitation is that the data do not include non-labor costs (e.g., pharmaceuticals, supplies, and non-visit labor costs). It is not known how the performance of potential case-mix adjustors would change if different measures of resource use were available that more fully reflected the total cost of care. Further, the study does not rule out the viability of alternative case-mix adjustors that could not be created for this study from the available data.

5.2.3 MedPAC Report June 2008

In addition to reporting updated trends in use, diagnoses, and length of stay within the hospice program, MedPAC’s 2008 report also included results from a RAND study that assessed visit-level data from the same large, national for-profit hospice chain that provided data for the MedPAC 2006 report (MedPAC, 2008). The chain provided data for 250,000 Medicare patients at 44 hospices in 17 states between 2002 and 2007, which accounted for approximately 5% of the Medicare beneficiaries who received hospice care during that time period. Most beneficiaries were from three states (Texas, Florida, and California). The data included visit-level variables for patients, such as type of visit, visit location, and visit start/end times. This information was aggregated to construct individual-level hospice episodes.

The findings from RAND’s study were consistent with the trend in data from broader analyses of Medicare’s hospice program. For example, the hospice chain’s mix of Medicare patients had shifted over time to include a greater share of patients with non-cancer diagnoses, and its average length of stay for Medicare patients increased from 44 days in 2002 to more than 83 days in 2007. This increase in length of stay was linked to patients with particular types of non-cancer diagnoses. For example, while the average length of stay for patients with cancer increased by only 21% (38 days to 46 days) between 2002 and 2007, the average length of stay for patients with neurological conditions in the same time period increased 130% (about 60 days to 138 days). The average length of stay increased by 71% (66 days to 113 days) and 92% (38 days to 73 days) for patients with nonspecific debility and all other non-cancer diagnoses, respectively.
MedPAC examined average visits per week and staffing of the visits, both of which affect a hospice providers’ profitability. The results showed variation across diagnoses in average hospice visits per week during this same time period. Specifically, while cancer patients received 6.1 visits per week from 2002 to 2007, the average visits per week of non-cancer patients declined: average hospice visits per week for neurological patients declined from 5.8 to 5.5; patients with nonspecific debility experienced a similar decline from 5.5 to 5.3; and patients with all other non-cancer diagnoses showed the most pronounced decline from about 6.1 visits to 5.4 visits (that is, a decline of 13%).

More broadly, the analysis revealed higher visit intensity for shorter stays and lower visit intensity for longer stays regardless of patient diagnosis. MedPAC’s analysis of staffing revealed that while the ratio of registered nurse (RN) or licensed practical nurse (LPN) visits to home health aides visits remained constant for cancer patients from 2002 to 2007, it declined for non-cancer patients.

Together, these findings suggest that long-stay patients (who typically have non-cancer diagnoses) may be more profitable for hospice providers than short-stay patients (who typically have cancer diagnoses) because of declines in average number of visits and use of less expensive staffing for the visits.

### 5.2.4 MedPAC Report March 2009

Based on its prior and current studies’ findings, MedPAC’s 2009 report discussed several significant changes in Medicare’s hospice program that affected Medicare hospice payments (MedPAC, 2009). For instance, hospice use in the Medicare population had increased dramatically, with the number of total Medicare beneficiaries utilizing hospice care nearly doubling between 2000 and 2007 (513,000 and 1 million, respectively). In the same time-frame, the number of providers offering hospice services increased from 2,319 to 3,261, with almost all of the increase occurring in for-profit hospices. MedPAC suggested that, while some of this increase was in response to increasing demand for hospice services, a large part of the increase may also have been due to financial incentives in Medicare’s hospice payment system, under which long stays are more profitable than short stays. MedPAC found that there was a pronounced increase in average length of stay between 2000 and 2005, while median length of stay remained virtually unchanged. Given that profitability and average length of stay increase in tandem, this result implies that the payment system rewards hospices that admit and care for patients who are more likely to have long stays.

MedPAC also noted the persistence of very short stays, which are also problematic for providers and patients alike. When hospice stays are very short, hospice providers have little opportunity to recoup their beginning- and end-of-episode costs, often resulting in negative financial margins. Meanwhile, patients with short hospice stays do not generally have time to fully benefit from all the hospice services. MedPAC noted that very short hospice stays may be a result of financial incentives that may lead acute-care providers to continue treating patients, resulting in a delayed referral to hospice after significant use (and expenditures) of acute health care services, or after a patient has used all of his/her Medicare-covered skilled nursing facility days. Alternatively, families, physicians, and patients reluctant to recognize a terminal situation may also lead to short hospice stays. Therefore, MedPAC stressed the need to create incentives for hospices to more appropriately admit patients such that they are able to fully benefit from hospice services.

Based on findings that hospice resource utilization and costs follow a U-shaped curve—that is, they are higher at the beginning and end of hospice stays (discussed above)—MedPAC recommended that payment for long-stay episodes of hospice care be modified such that reimbursement levels vary based on the day of the hospice stay. With the qualification that CMS would need to determine the
actual weights, MedPAC provided illustrative examples of possible weights to use in an intensity-adjusted payment approach. Their examples maintained the consistent pattern that there would be a higher weight for the first 30 days and last seven days of the care episode, with a step-down weight for intervening time frames of 31–90 days, 91–180 days, and days 181 and over. MedPAC noted that the payment increase for the final seven days would only apply in cases where the episode ended with the patient’s death (not when the patient revokes the benefit, moves to a different hospice, etc.). Also, there would not be additional higher payments if the death happens within the first 30 days (e.g., the final seven days payment is only included if the episode ends in death after the first 30 days).

MedPAC presented the intensity-adjusted payment strategy as one way to address issues related to length of stay and time of enrollment, positing that the current payment methodology does not take into account varying resource needs at the beginning, middle, and end of a hospice episode, particularly for episodes that are extended (greater than six months). Potential benefits of the intensity-adjusted approach include better management of the incentives in the present payment system that encourage admission of longer stay patients with less intense service needs. The intensity-adjusted approach could remove the disincentive for hospices to admit patients likely to have short stays.

5.2.5 MedPAC Report March 2010

Beginning July 1, 2008, hospices were required to report the number of visits each week provided by nurses, home health aides and social workers on their Medicare claims (MedPAC, 2010c, 2010d). MedPAC used these newly available data to perform an analysis of hospice visit patterns. They used claims for patients admitted and discharged within the first six months of the reporting period (i.e., July 1, 2008 through December 31, 2008). Additionally, patient-level proprietary data for approximately 120,000 Medicare patients across 14 states were obtained from a group of 17 non-profit hospice providers that reported frequency and length of visits by type of personnel for October 1, 2005 through September 30, 2008.

**Frequency and length of visits:** Consistent with previous findings discussed above, MedPAC’s analysis of the two new data sources found that patients with shorter hospice stays had more visits per week on average than patients with longer stays. While the number of visits varied according to length of stay, a U-shaped pattern of visits was consistent across all lengths of stay with more visits occurring in the first seven days following admission and last seven days before death compared to the middle of the episode of care, as indicated in Figure 1, below. Patients with a length of stay lasting 31–60 days had an average of 5.6 visits during the first seven days of care and 6.7 in the final seven days of care compared to 4.3 visits during the other days of care (MedPAC, 2010c). Using the proprietary data, MedPAC found that, similar to the frequency of visits, the average duration of the visits was higher for shorter stays than longer stays. Neither visit hours nor the number of visits varied across diagnoses after accounting for length of stay.
5. Findings Related to the Research Questions

Staffing of visits: Overall, both data sources indicated that patients with shorter stays had more visits from nurses compared to home health aides. The data also indicated that after accounting for length of stay, patients with cancer tended to receive more visits from nurses than patients with non-cancer diagnoses.

Location of visits: Across all lengths of stay, nursing facility residents and patients in an assisted living facility received slightly more hospice visits than patients cared for in a private home. For example, the average total visits per week for patients with a 31–60 day length of stay was 5.2 in a nursing facility and 5.4 in an assisted living facility compared to 4.8 for patients residing in a private home. The staffing of the visits also varied by location, with hospice patients residing in nursing facilities and assisted living facilities receiving more home health aide and fewer nursing visits than patients in a private home. For example, the average total visits per week by a home health aide for patients with a 31–60 day length of stay was 1.8 for patients residing in a private home versus 2.3 in a nursing facility and 2.2 in an assisted living facility. This pattern persisted regardless of the length of stay. MedPAC provided several possible reasons for provision of more visits (particularly aide visits) to nursing facility residents, including: convenience of providing care to multiple residents in a central location; less availability of family caregivers for nursing facility residents compared to home-dwelling hospice clients; and substitution of hospice visits for care that would ordinarily be provided by nursing facility staff.

Hospice provider characteristics: The average number of visits did not vary substantially based on the size of the hospice or whether the hospice was located in a rural versus urban location. However, adjusting for length-of-stay, freestanding, home health-based and for-profit hospices provided slightly more visits from home health aides than other provider types, resulting in higher total visits per week.

5.2.6 MedPAC Report March 2011

MedPAC’s March 2011 Report examined hospice margins from 2002 to 2008 to assess how current costs to providers compare to Medicare payment (MedPAC, 2011). They concluded that, while overall payments were adequate, financial performance under Medicare varied considerably, suggesting a need for refinements in hospice payment methodology.
MedPAC used cost report and claims data from 2002 to 2008 to calculate the aggregate Medicare margin based on Medicare allowable, reimbursable costs while excluding Medicare overpayments to hospices that exceeded the annual hospice cap. Costs were aggregated for all four levels of care (routine home care, continuous home care, general inpatient care and inpatient respite care) and included the total number of days the hospice was responsible for the patient. Costs per day were not adjusted for case mix or wages across hospices. The calculation for the aggregate Medicare margin was based on the following formula:

\[
\text{Aggregate Medicare Margin} = \frac{(\text{Sum of total payments to all providers}) - (\text{Sum of total costs for all providers}))}{\text{(Sum of total payments to all providers)}).
\]

That is, the Medicare margin can be viewed as an indicator of the adequacy of Medicare payments relative to hospices’ costs.

The aggregate Medicare margin was 5% in 2008 but varied widely across providers, ranging from -16% at the 25th percentile to 19% at the 75th percentile. MedPAC reported similarly positive margins for 2002–2007, ranging from 4.6 to 6.6%. Estimates excluded non-reimbursable costs of bereavement services (approximately 1.5% of total costs) volunteer services (approximately 0.3% of total costs), and fundraising costs (approximately 1.5% of total costs). Revenues from donations were also excluded (both for-profit and non-profit hospices solicit donations).

Between 2002 and 2008, higher margins were observed among freestanding, for-profit, and urban hospices compared to their counterparts. In 2008, freestanding hospices had margins of 8% compared to margins of 3% and -12% for home health-based and hospital-based hospices, respectively. Differences in margins across freestanding, home health-based, and hospital-based hospices are partly due to differences in indirect costs, which are higher for provider-based hospices and are likely inflated because of the allocation of overhead costs from the parent provider.

In 2008, for-profit hospices had 10% margins compared to 0.2% among non-profit hospices, and there were also substantial margin differences among freestanding non-profit hospices (3%) and hospital-based non-profit hospices (-11%). The lower margin for hospital-based hospices partly reflects differences in indirect costs, which are higher for provider-based hospices and likely inflated due to allocation of overhead costs from the parent provider. Urban hospices had 6% margins compared to 1% for rural hospices. In general, larger hospices and hospices with longer lengths of stay had higher profit margins than their counterparts. Above-cap hospices had higher margins (19%) than below-cap hospices (6%) in 2008.

In summary, the report concluded that overall hospice payments appeared to be adequate, but that there are incentives for long stays that may lead to inappropriate use by some providers.

### 5.2.7 MedPAC Report March 2012

In their March 2012 report, MedPAC describes a series of metrics that were evaluated to understand whether Medicare payments adequately cover current and forecasted (2013) costs for providers. Specifically, MedPAC examined beneficiaries’ access to care by examining the capacity and supply of hospice providers and changes over time in the volume of services rendered, quality of care,
providers’ access to capital and the association between Medicare payments and providers’ costs (MedPAC, 2012). MedPAC concluded that current payments should appropriately cover costs for efficient providers.

**Beneficiaries’ Access to Care:** From 2000 to 2010, the total number of hospices in the United States increased by 53% (2,300 to 3,500 total hospices). For-profit hospices accounted for the bulk of this growth, with the number of for-profit hospices increasing by 150%. During this same time period, the number of nonprofit hospices decreased by 1%, while government and other ownership type hospices grew by 27%. This growth in the number of hospices occurred predominantly among freestanding providers and was not dependent on rural or urban status. In terms of volume of services, the total number of hospice services rendered increased by 0.6 million between 2000 and 2010, representing an average annual rate of increase of almost 9% per year. Average lifetime length of stay accompanied this increase, with the average length of stay growing from 54 days in 2000 to 86 days in 2010. MedPAC concluded that the main driver behind the increase in average length of stay was an increase in very long hospice stays. For example, when looking at the 90th percentile of long stay patients, MedPAC found that the average length of stay for these beneficiaries increased from 141 to 249 days between 2000 and 2010. MedPAC has suggested that the increase in the length of stay for long stay patients, as well as very short stay patients, is concerning. The increase in very long stay patients may reflect the hospice industries pursuit of business models to obtain patients who do not meet hospice eligibility criteria and subsequently have longer stays. Conversely, beneficiaries with very short stays may not fully benefit from receiving all hospice services.

**Quality of Care:** As reported by MedPAC, sufficient data are not available to evaluate the quality of hospice care delivered to patients. However, the Patient Protection and Affordable Care Act mandates CMS to publish hospice quality measures by 2012 and CMS has already adopted two quality measures for reporting for FY 2013.

**Provider’s Access to Capital:** MedPAC has concluded that providers’ access to capital is adequate. Upon review of publically available financial reports, MedPAC found that many publically traded companies providing hospice care have recently reported strong revenue growth. In terms of private equity groups the number of merger and acquisition transactions for hospice providers has increased since 2010. These indicators, in addition to the immense increase in the number of for-profit hospice providers, have led MedPAC to conclude that providers’ access to capital is adequate.

**Medicare Payments and Providers’ Costs:** The projected average margin for hospice providers in 2012 is 5%, a 2 percentage point decrease from 2009. Medicare margins tend to be higher for hospices serving beneficiaries in urban areas compared to rural areas.

5.2.8 **Summary: Costs, Payment Adequacy and Accuracy of Hospice Care**

In summary, the mix of services used to provide routine home care has changed over time, with some components increasing (e.g., pharmaceuticals and medical equipment) and others decreasing (home health aide and outpatient services). Research suggests that most of the variation in hospice resource use can be explained by the number of days of care, suggesting that hospice patients have similar care needs, regardless of diagnoses and patient characteristics. Results using patient-specific data show that hospice visits tend to be concentrated at the beginning and end of hospice stays; resulting in a U-shaped cost model, with the costs of care being higher at both the beginning and end of a hospice stay. This U-shaped pattern is consistent for both short and long lengths of stays. Despite the
persistence of very short hospice stays (less than seven days), the average length of stay for hospices has increased over time, largely driven by a rise in patients with non-cancer diagnoses. This has resulted in higher profit margins for some hospices with more non-cancer patients, who tend to have longer stays and receive fewer visits per week from less skilled staff. Other provider characteristics associated with higher profit margins include hospices that are above-cap, larger, freestanding, for-profit, and that operate in an urban setting. Smaller hospices and hospices in rural settings tend to have higher per diem costs and likely lower payments from Medicare, a combination that leaves these types of facilities at a financial disadvantage.

5.3 Identifying Payment System Vulnerabilities

- What are the vulnerabilities or perverse incentives that encourage over-use or under-use of hospice care?
- What considerations are important in reforming the payment system to minimize perverse incentives without unduly impeding access to hospice care?

In addition to the payment adequacy and accuracy concerns discussed above, vulnerabilities in Medicare’s hospice payment system also exist that may allow unwarranted care to be provided and makes compliance with coverage requirements a continued area of concern for Medicare regulators. This section summarizes research that has examined questionable billing practices stemming from compliance issues, live discharges, and the hospice aggregate cap.

5.3.1 Compliance Issues and Questionable Billing Practices Identified by Office of Inspector General (OIG)

OIG has issued a series of reports on hospice care that examine a variety of issues, including compliance and coverage requirements for nursing home residents (OIG, 2009). For the study, two registered nurses with hospice care experience reviewed the medical records associated with a random sample of 450 Medicare hospice claims from 2006 to determine whether they met Medicare coverage requirements for beneficiaries residing in nursing homes. The Minimum Data Set (MDS) was used to identify hospice stays that occurred in nursing facilities. The study focused on the following coverage guidelines:

1. The individual must elect hospice care in accordance with regulations.
2. A plan of care must be established as set forth in regulation before services are provided.
3. The services must be consistent with the plan of care.
4. A certification that the individual is terminally ill must be completed as set forth in regulation.

The OIG found that over 80% of hospice claims did not meet at least one of Medicare’s requirements. Of the four coverage requirements, meeting the plan of care was most common failure (63% of claims). This encompasses a variety of deficiencies of the care plans, including omitting the scope of a type of service, the plan of care not being established by an interdisciplinary group or not specifying intervals for review of the plan. Conversely, just 4% of claims failed to meet one or more certification of terminal illness requirements. A third of the claims did not meet one or more of the election requirements, which included misleading language for some of the election statements. The study found that 31% of claims were for fewer services than the number specified in the plan of care.
Compared to for-profit hospices, the OIG found that non-profit hospices were significantly less likely to meet three of the four Medicare requirements (there was no difference between providers for the number of services provided compared to what was specified in the plan of care). Based on these findings, the OIG recommended that CMS improve its monitoring practice and provide educational materials and tools to hospices with particular attention to non-profit hospices.

More recently, the OIG identified questionable billing practices for physician services under Medicare Part A and B for beneficiaries receiving hospice in 2009 (OIG, 2010). The OIG identified over 9,000 Part B claims totaling $566,000 for hospice services that were provided by the same physician who billed on the Part A claim for services related to the patient’s terminal illness. These questionable claims were submitted by 3,166 physicians for 4,280 hospice patients. One-third of the claims were from Florida, and these accounted for 35% of the total questionable reimbursement amount, followed by North Carolina which accounted for 11% of the total. The OIG also found that six of the ten physicians with the highest levels of questionable billing practiced in Florida, and three of the ten shared the same mailing address. Although it is unclear whether the hospice billed incorrectly or if the physician incorrectly used the Part B modifier, the OIG’s findings illustrate the hospice program’s vulnerability because of the ability to bill under both Medicare Part A and Part B.

In 2011, the OIG published a report that focused specifically on spending for hospices who served a high percentage of nursing facility residents. OIG found that from 2005 to 2009, the total Medicare spending for hospice care for nursing facility residents increased from $2.55 billion to $4.31 billion, an increase of almost 70% (OIG, 2011). For-profit hospices were found to be reimbursed 29% and 53% more per beneficiary than non-profit and government-owned hospices, respectively. When looking at hospices that had more than two-thirds of their beneficiaries in nursing facilities, OIG found that 72% of these facilities were for-profit. OIG also found that these high-percentage hospices received an average payment of $3,182 more per beneficiary than hospices overall. Further, high-percentage hospices were found to serve beneficiaries who spent more days in hospice care, to the magnitude of three weeks longer than the average beneficiary. When looking at distributions in diagnoses, OIG found that high-percentage hospices enrolled beneficiaries who required less skilled care, such as those with cognitive impairments. In response to these findings, OIG suggested 1) increased monitoring of hospices serving high percentages of beneficiaries in nursing home facilities to ensure that these hospice are meeting Medicare requirements, and 2) modification to the current hospice reimbursement system to lessen the incentive for hospices to seek out beneficiaries in nursing facilities, who often receive longer but less complex and costly care (OIG, 2011).

Lastly, in 2012, OIG published a report warning Medicare that it could be paying twice for prescription drugs for beneficiaries enrolled in hospice. For example, when examining analgesics, anti-nausea, laxatives and anxiety prescription drugs, OIG found that these drugs were often being paid for by Medicare Part D, despite the fact that they probably should have been covered by hospice. In CY 2009, this equated to close to 27 million dollars in prescription drug costs for Medicare Part D and over 3 million dollars in copayments for hospice beneficiaries (OIG, 2012). OIG found similar results when examining drugs for specific conditions (e.g. ALS, COPD, etc.). In response to these findings, OIG recommended that CMS address this issue by performing the following: 1) notifying hospice providers and pharmacies that it is inappropriate for Medicare Part D to pay for drugs related to a beneficiary’s terminal illness; instead hospices should be covering these drugs, 2) conducting oversight to ensure Part D is not paying for prescription drugs that have already been covered under per diem hospice payments and 3) requiring hospice providers and pharmacies to develop controls.
that prevent Part D from paying for drugs that are covered under per diem hospice payments (OIG, 2012).

5.3.2 Patient/Hospice Characteristics Related to High Rates of Live Discharge

It is expected that some patients would be discharged alive from hospice either because the patient’s illness did not follow the expected course (e.g., the patient’s cancer went into remission), or because the patient decided to revoke his or her hospice election to resume curative treatment. Estimates of the percentage of patients who are discharged alive from hospice have ranged from 11% to 21% (Carlson et al., 2009, 2010b; Taylor et al., 2008; Kapo et al., 2005). Researchers have found that patients who are discharged alive from hospice have longer hospice stays, are healthier at time of enrollment, and require fewer resources during their time in hospice compared to other hospice patients. These findings suggest that profit margins are higher for these patients, and that some patients may have been admitted before they were terminally ill with a prognosis of 6 months or less to live.

In a study of nursing home residents receiving hospice care, Huskamp et al. (2010b) studied a large regional hospice that mainly provides care to nursing home residents (n=13,479). The study found that the median length of stay was longer for patients who were discharged from hospice due to ineligibility than for patients who remained enrolled until their deaths (134 days vs. 17 days). In a nationally representative sample of Medicare beneficiaries with FFS coverage who died between 1993 and 2000 (n=1,218), Taylor et al. (2008) found that patients discharged alive from hospice survived significantly longer on average than patients who remained in hospice care (280 days after initial hospice enrollment vs. 50 days), suggesting that these patients were healthier when they were admitted to hospice. MedPAC found that live discharge patients received fewer visits per week during their time in hospice than patients with a similar length of stay who remained in hospice continuously until their death (MedPAC, 2010c).

Carlson et al. (2010b) found that patients with cancer who were discharged alive from hospice were significantly more likely than those who remained in hospice to be hospitalized (40% vs. 2%) and to die in the hospital (10% vs. 0.2%). Likewise, Taylor et al. (2008) found that patients discharged from hospice prior to death were significantly more likely to use inpatient care than those who remained enrolled in hospice (3% vs. 31%). Taylor et al. (2008) suggest that these findings indicate that patients who were discharged from hospice alive may have left hospice to seek curative treatment. Carlson et al. (2010b), however, found that cancer patients who were discharged alive from hospice died an average of 24 days after their discharge, suggesting they did not leave hospice due to improved health status.

Research findings are contradictory, however, in regards to how live discharge from hospice affects Medicare costs. Carlson et al. (2010b) found that patients who were discharged alive incurred per-day Medicare expenditures that were significantly higher ($124) than those who remain in hospice care. Taylor et al. (2008), however, found that there was no significant difference in per-day Medicare expenditures between patients who were discharged alive compared to those who remained in hospice ($152 vs. $185). MedPAC found that hospices that exceeded the annual cap had substantially higher rates of live discharges (44%) than hospices that did not exceed the cap (16%) (MedPAC, 2011). This pattern of higher live discharge rates among above-cap hospices was consistent across all diagnostic categories, and even more pronounced among non-cancer diagnoses (for example, 55% of discharges related to heart/circulatory diagnoses were live discharges at above-cap hospices compared to just 15% at below-cap hospices) (MedPAC, 2011). The high rate of live discharges among above-cap
hospices raises concerns that some hospices may be admitting patients before they meet hospice eligibility criteria and as a result are delivering poorer quality care that is disruptive to beneficiaries and their families.

Hospice discharge rates have been found to vary by hospice characteristics. In a study of Medicare FFS cancer patients in hospice care (n=90,826), Carlson et al. (2009) found that live discharge rates were significantly higher among newer hospices, smaller hospices, and hospices located in competitive markets. However, the researchers also found that neither type of ownership nor geographic density (urban vs. rural location) was significantly associated with live discharge rates (Carlson et al., 2009). Bain et al. (2009) found that live discharge rates were lower among patients receiving care in long term care facilities.

An increase in hospice care for conditions with less predictable trajectories may also contribute to higher rates of live discharges. Bain et al. (2009) compared patients with heart failure (n=11,754) with cancer patients (n=31,228). The study found that cancer patients were significantly less likely to be discharged alive from hospice than heart failure patients, whose health is more prone to fluctuation over time (11% vs. 19%). In contrast to this finding, however, a study of Medicare beneficiaries without managed care who used hospice and died 1993 to 2000 (n=1,218) by Taylor et al. (2008) did not find any significant differences in live discharge rates based on cancer versus non-cancer diagnoses.

Findings about the role that race or ethnicity plays in the rate of live discharges are mixed:

- Carlson et al. (2009) noted that white non-Hispanic patients were significantly less likely to disenroll from hospice than were white Hispanics (OR=1.24), African Americans (OR=1.51) or patients with a race/ethnicity designation of “Other” (OR=1.61).
- Bain et al. (2009) (n=42,982) found a significant positive correlation between African Americans and likelihood of live discharge.
- After controlling for demographic and hospice use variables, Johnson et al. (2008) found that African Americans were significantly more likely than white patients to revoke hospice to pursue aggressive hospital-based care (5% vs. 3%).
- Taylor et al. (2008) found no significant differences in live discharge based on ethnicity.

### 5.3.3 Characteristics of Hospices Exceeding Medicare’s Annual Aggregate Cap

As discussed in the background section, CMS applies an inpatient cap to limit total inpatient days, and an aggregate reimbursement cap to limit total Medicare payments (CMS, 2010a). The aggregate cap is applied to total payments received by a hospice provider rather than at the beneficiary level; the cap amount was $23,874.98 for FY 2010 (CMS, 2010d) and $24,527.69 for the 2011 cap year (CMS, 2011a). Hospices that exceed either cap are required to refund the excess payments to Medicare (MedPAC, 2011).

The inpatient cap is seldom exceeded by hospices (MedPAC, 2011), and GAO analyses using Medicare claims from 1999 and 2002 showed that less than 2% of facilities exceeded the aggregate payment cap (GAO, 2004). However, more recent analyses from MedPAC shows that the number of hospice providers exceeding Medicare’s aggregate cap is increasing, from 4% in 2003 to 10% in 2007, and also exceeded 10% in 2008 (MedPAC, 2010a, 2010d). This resulted in $208 million in
total dollars of cap overpayments in 2007, which represents approximately 2% of total hospice payments (MedPAC, 2010d).

Using 2002–2005 claims data from four regional home health intermediaries, MedPAC identified several characteristics common to hospices exceeding the aggregate cap (MedPAC, 2008). These included for-profit status, being freestanding, operating in an urban setting, and having a smaller patient load (approximately half the patient load as compared to hospices that did not exceed the cap). Although above-cap hospices had a higher percentage of patients with diagnoses associated with typically longer lengths of stays (that is, above-cap hospices had a lower percentage of cancer cases compared to below-cap hospices), patient case mix did not entirely explain a hospice’s proclivity to exceed the cap since above-cap hospices had longer stays across all diagnoses. Using 2007 data, MedPAC found that 41% of all stays in above-cap hospices exceeded 180 days compared to only 18% in below-cap hospices (MedPAC, 2010d). Similarly, 19% of hospice beneficiaries with a cancer diagnosis (who tend to have a less variable disease course than patients with Alzheimer’s and other non-cancer diagnoses) and 50% of patients with a neurological diagnosis in above-cap hospices exceeded 180 days compared to only 9% and 20%, respectively, in below-cap hospices (MedPAC, 2010d). As discussed in the section above, above-cap hospices also have a substantially higher rate of live discharges than below-cap hospices. These observations suggest that hospices exceeding the cap may preferentially enroll patients who are expected to live longer, and may be inappropriately enrolling patients who are not yet eligible for hospice care.

Although some hospice providers assert that the aggregate cap limits beneficiaries’ access to hospice, MedPAC’s analysis did not find evidence for this claim, citing the growth in number of hospice providers as well as volume of hospice care, regardless of the number of hospices in the area exceeding the aggregate cap (MedPAC, 2008). Their finding that hospice care delivery differs significantly between hospice providers that exceed Medicare’s annual cap and those that do not represents an important consideration in payment reform.

**5.3.4 Summary: Payment System Vulnerabilities**

There are several characteristics of the hospice payment system which make it vulnerable, including the ability to bill physician services to hospice patients under both Medicare Part A and Part B. Additionally, an OIG investigation found that most hospice claims they reviewed did not meet at least one of Medicare’s mandatory requirements for provision of hospice care, suggesting more oversight and education of hospices are needed. The growing number of hospices exceeding the annual cap is also an indicator of possible payment system vulnerability, since findings suggest that these hospices may preferentially enroll patients who are expected to live longer and may be inappropriately enrolling patients who are not yet eligible for hospice care. Above-cap hospices have substantially higher rates of live discharge than those not exceeding the cap. Although it is expected that some patients would be discharged alive from hospice, researchers have found that these patients have longer hospice stays, are healthier at the time of enrollment, and require fewer resources during their time in hospice compared to other hospice patients. This suggests that profit margins are higher for these patients and that some patients may have been admitted before they were eligible for hospice, signifying another vulnerability to the hospice payment system.
5.4 Responding to Proposals for Payment Reform

- How should the payment system be reformed to minimize perverse incentives without impeding access?
- What is the evidence to support payment reform proposals?

Several prior studies have suggested that a per diem payment system for routine home care (which accounts for 95% of all hospice care days) that provides the same level of payment throughout a stay is not well aligned with the costs incurred by hospices (GAO, 2004; MedPAC, 2006, 2008, 2009, 2010d; Huskamp et al., 2008). This payment methodology does not account for variation that occurs in the number, duration or mix of visits across hospice stays. Ideally, hospice payment would promote hospice enrollment early enough in the disease trajectory to allow delivery of the range of services necessary to promote comfort, while also discouraging very short stays, when a patient has little time to benefit from hospice services and after significant costs associated with acute medical care have often been incurred. Additionally, the payment methodology should discourage the incentive to provide long-stays that is present in the current payment system. Stevenson (2012) and Taylor (2012) also raise the notion that payment systems should incentivize the integration of hospice care into the continuum of healthcare services, closely align with the needs of patients, and conform to the realities of the U.S. healthcare delivery system today. This section summarizes various approaches recommended to refine the hospice payment system such that payment is better aligned with the utilization observed in the data.

5.4.1 Case-Mix or Outlier Adjustments

One option for payment reform would be to apply a case-mix adjustment to account for different patient characteristics, as is done in other Medicare payment systems (e.g., hospital care, home health, skilled nursing facilities, long-term care hospitals, rehabilitation care). However, analyses using data from a large national hospice chain that accounted for approximately 6% of Medicare hospice patients admitted in 2002–2003 suggest that case-mix is not an important predictor of hospice resource use (MedPAC, 2006; Nicosia et al., 2009). The research conducted by RAND (reported in MedPAC, 2006 and Nicosia et al., 2009) found that although many of the patient characteristics (e.g., diagnosis, age, race, sex) were statistically significant predictors of resource use (as measured by number of visits and visit labor costs), they explained little of the variation in resource use (less than 12%). The population used in the analyses differed from the overall Medicare hospice population, which may have contributed to the relatively poor statistical performance. For example, the chain’s patients tended to be older with fewer lung cancer and debility diagnoses and less likely to be white. Furthermore, the analysis relied on data from a single chain that may have more homogeneous practice patterns than all Medicare hospice providers, limiting the generalizability of the results. Nevertheless, the researchers concluded that patient case-mix adjusters do not appear to be a meaningful predictor of hospice resource utilization.

Though RAND’s research indicates that case-mix is not an important predictor of resource use in hospice care, Legler et al. (2011) suggests that hospice reimbursement rates may indeed need to be risk adjusted for hospices caring for patients with higher comorbidity burdens. In a study of hospice patients who died of cancer in 2002 (n=27,166), it was found that higher patient comorbidity burden, as measured by the Charlson comorbidity index, was associated with a higher likelihood of inpatient hospitalization, as well as emergency department and ICU admissions (Legeler et al., 2011).
Similarly, other researchers have suggested that CMS consider an outlier adjustment to the payment system to account for patients who require excessively expensive hospice care, such as expensive anti-cancer medications (Huskamp et al., 2008). The authors were unable to explore different outlier systems due to data limitations, but noted that the absence of a mechanism for such outliers may translate to restricted access for patients with high care needs and significant financial strain for small hospices.

### 5.4.2 Intensity-Adjusted Payment (U-Shaped Payment Model)

Analyses by GAO, MedPAC, and other researchers have consistently shown higher resource utilization at the beginning of the episode, followed by relatively lower use each day as length of stay increases, and then higher resource use in the days preceding death (GAO, 2004; MedPAC, 2006, 2008, 2009; Huskamp et al., 2008). Therefore, recent recommendations favor retaining the current per diem payment structure, but reforming the system in a manner that more accurately reflects resource use with a payment system with higher payments at the beginning of the episode, relatively lower payments per day as length of stay increases, and relatively higher payments for the costs associated with death (MedPAC, 2009). MedPAC modeled the effect of implementing a U-shaped or “intensity-adjusted” payment model on hospice payment and found that the model more accurately aligns resource intensity with payment while simultaneously reducing the number of hospices exceeding the cap and discouraging very long stays. In this intensity-adjusted model, hospices would continue to be reimbursed on a per diem basis, but payment weights would be applied such that payment would be relatively higher during the initial and final days of care, and payments would be lower in the middle of stays to reflect the lower resource utilization observed in the data. The varying payment amounts could be weighted to maintain budget neutrality.

MedPAC’s 2009 report analyzed the performance of a payment system that gave hospices a relatively higher payment during the initial 30 days of care and the final seven days of care (with no end of episode payment if the patient died in the first 30 days). They employed two illustrative examples with varying weights (Table 6, below).

**Table 6: MedPAC’s Illustrative Examples of Weights for Intensity-Adjusted Payment System**

<table>
<thead>
<tr>
<th>Day of Hospice Stay</th>
<th>Weights for Intensity Adjustment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Larger</td>
</tr>
<tr>
<td>1–30</td>
<td>2</td>
</tr>
<tr>
<td>31–90</td>
<td>1</td>
</tr>
<tr>
<td>91–180</td>
<td>0.5</td>
</tr>
<tr>
<td>180+</td>
<td>0.25</td>
</tr>
<tr>
<td>last 7 days</td>
<td>2</td>
</tr>
</tbody>
</table>


MedPAC estimated that an intensity-adjusted payment system would decrease the number of hospices exceeding the cap by 26 or 45%, depending on the size of the intensity adjustment. The majority of hospices (approximately 58%) would experience increases in payment by greater than 2%, a third (34%) would experience decreases in payment by greater than 2%, and 8% would experience changes of less than 2% (MedPAC, 2009). The magnitude of the impact is correlated with average length of stay: 97% of hospices who are in the lowest quintile of stays exceeding 180 days would experience increases in payment by greater than 2%, whereas 78% of hospices in the highest quintile of
proportion of stays exceeding 180 days would experience payment declines greater of 2% or more. MedPAC also reported on changes in aggregate payments for several subgroups:

- **Long stays (>180 days)**: 16.6–24.1% increase in payments for hospices in the first quintile, and 6.6–10.8% decrease for hospices in the last quintile
- **Profit status**: 2.5–4.1% increase in payments for non-profit hospices, and 3.2–5.0% decrease for for-profit hospices
- **Hospice type**: 7.8–10.9% increase in payments for home health and hospital-based hospices, and 2.3–3.2% decrease for freestanding facilities
- **Urban/rural**: 2.2–2.8% increase in payments for rural hospices, and 0.3–0.4% decrease for urban hospices

Given differences in average stay length, MedPAC (2009) also recommended that OIG examine hospice marketing materials and the enrollment practices for hospices with unusual utilization patterns (e.g., very long or very short stays) to ensure they are accurate and appropriate.

More recently researchers have found that other measures of hospice utilization and cost also follow a U-shaped curve over a patient’s hospice stay. Gibson et al. (2012) found that medication costs for hospice patients occur in a U-shape, similar to the shape described in MedPAC’s reports, with the highest medication costs coming in the first and last weeks of hospice care. However, because medication costs were observed to drop on average 52% from the first week to the “interim period” (middle of hospice stay) and increase 102% from the “interim period” to the last week, Gibson et al. concluded that overall hospice reimbursement should not decrease by more than 50% of the initial reimbursement any time during a patient’s hospice stay. Overall reimbursement was also recommended to be adjusted for drug cost trends, hospice diagnosis mix and medication appropriateness.

### 5.4.3 Payment for Hospice Care in Nursing Homes

Several payment strategies have been aimed at hospice care provided in nursing homes, stemming from research that has examined variation in and provision of hospice care in nursing homes. Huskamp et al. (2008) found that total hospice costs (as well as average personnel, pharmacy, and DME costs per day) were lower for nursing home residents compared to non-resident hospice patients, which suggests possible financial benefits for hospices to serve patients in nursing homes. The cost savings stems from potential overlap between nursing homes and hospice services. Furthermore, travel costs for hospice staff are likely to be lower since several hospice patients may be at a single nursing home. Based on their findings, the authors suggested that CMS explore whether the hospice per diem rate should be adjusted downward for nursing home residents so that reimbursement more closely matches actual costs.

Looking at Florida nursing home residents who died in the latter half of 1999, Miller et al. (2004) found total government expenditures (i.e., Medicaid and Medicare) to be significantly lower for the last month of life for nursing home residents with hospice compared to those without hospice. The authors also reported expenditures by short-stay (i.e., 90 days or less) and long stay (i.e., 90 days or more) residents: expenditures were significantly lower for the last month and last six months of life for short-stay nursing home residents with hospice compared to those without hospice, but this relationship did not hold for long-stay nursing home residents. The authors observed that much of the observed differences in government expenditures between the hospice and non-hospice residents
stemmed from differences in expenditures related to acute inpatient care. Based on their findings, the authors concluded that it was appropriate to encourage hospice for both short and long-stay nursing home residents—for long-stay residents, this is because of how hospices can improve end-of-life care rather than for reducing Medicare expenditures. In light of the government cost savings observed for short-stay nursing home residents, the authors suggested Medicare consider modifying their benefit package to allow hospice services for Medicare beneficiaries who require skilled care in nursing homes. Given the differences in hospice costs, staffing, and length of stays between hospice patients in nursing homes versus other settings, MedPAC has recommended that OIG examine nursing home referral patterns to hospice and investigate the financial relationships between hospices and long-term care facilities since they may represent a conflict of interest that inappropriately influences admissions to hospice (MedPAC, 2009). More recently, researchers recommended a separate end-of-life Medicare benefit for nursing home residents that would require neither a physician’s certification regarding the patient’s prognosis, or for beneficiaries to choose between hospice and curative care (Huskamp et al., 2010a). Rather, all nursing home residents that met a threshold level of end-of-life care would automatically be eligible for hospice care, which the authors assert would improve access for many of nursing home residents who have limited family involvement or terminal illnesses with a more variable life trajectory (e.g., non-cancer diagnoses). Unlike the current payment system, nursing homes, not hospices, would be paid directly for the end-of-life care services, thus using a “carve in” approach that integrates the resident’s nursing home and hospice needs. Furthermore, the nursing home would be held accountable for providing high quality end-of-life care which the authors acknowledge would require creation of new quality measures appropriate for end-of-life care.

It is important to note that there are limitations to the analyses on which the recommendations or proposed approaches are based; for example, relying on data from a single hospice chain (Huskamp et al., 2008) or looking at a single state (Miller et al., 2004). Accordingly, additional analysis is required to determine how best to account for nursing home residents in hospice payment reform efforts. However, these studies illustrate some of the payment reform options currently in the literature related to hospice care provided in nursing homes.

5.4.4 Summary: Proposed Payment Refinements

In summary, numerous hospice payment refinements have been proposed, including having a case-mix or outlier adjustment to the hospice payment system to account for differences in patient characteristics. However, analyses suggest that these factors explain little of the variation in hospice resource use. Conversely, many researchers have observed a “U-shaped” pattern to hospice resource use: higher utilization at the beginning of the episode, relatively fewer visits per day as length of stay increases, and higher use in the days preceding death. Based on these findings, several researchers have recommended an intensity-adjusted payment model that more accurately reflects the observed resource use patterns. Given the variation in length of stay across different providers, such a refinement would likely affect hospice providers in different ways. Payment refinements specific to hospice care provided in nursing homes have also been considered, including a downward adjustment to the hospice per diem rate for nursing home residents. Researchers have also recommended a separate end-of-life Medicare benefit for nursing home residents where nursing homes would be paid directly for hospice services and held accountable for providing high quality end-of-life care. Most recently, calls have been made for a new payment model that addresses the difficulty in predicting the clinical course of hospice patients, varying utilizations patterns and transitions across care settings for
subpopulations, and the ability to support many different approaches to delivering hospice care (Unroe et al, 2013); however no such model has been proposed.
6. Limitations

In collaboration with Brown University’s Center for Gerontology and Healthcare Research, Abt Associates critically assessed the research findings cited in this review to identify potential study limitations that should be considered when using this review to inform hospice payment reform. Significant changes in the hospice industry and gaps in the literature were also considered. This section provides an overview of these limitations.

6.1.1 Methodological Limitations

Selection bias is a significant concern of the hospice literature. To evaluate the cost-saving benefits of hospice, studies are often conducted in a manner which compares utilization patterns and costs based upon hospice status (hospice vs. non-hospice). Since an individual can only receive one type of care at one point in time, it is therefore necessary to infer what an individual’s outcomes would be under the type of care not elected. A critical step in this type of analysis is to account for selective referral to hospice, as individuals who elect hospice may significantly differ on a number of characteristics from individuals who elect conventional care. Case-control and retrospective matched hospice studies missing important matching variables are thus at significant risk for selection bias (Gozalo et al, 2007; Gozalo et al., 2008). Prospective studies that match on patient utilization and health status characteristics over time are needed to account for selection bias concerns.

Generalizability is an issue for most hospice studies and especially for those studies that investigate the relationship between visits and hospice characteristics. There are a small number of studies which utilize visit data (GAO, 2004; MedPAC, 2006, 2008). However, all of these studies are from the same data source, which is representative of a national, for-profit hospice chain. Thus, the findings from these studies may not be directly applicable to small, non-chain or non-profit hospices. These studies are further limited because they do not contain information related to medications, therapy, durable medical equipment and supplies. Due to evidence that shows that some of these services may differ by for-profit status (Carlson et al., 2004), it will be difficult to predict how changes in reimbursement will effect costs if hospice payments are only based upon visit data. As detailed in the review, the hospice industry has dramatically changed over the last decade. Studies included in this review that precede these major changes, should be interpreted with caution as they may not accurately represent current hospice care. To better understand the impact of changes in the hospice industry and the differences in behavior between new and older hospices, additional research is needed.

6.1.2 Economic Study Gaps

There is a lack of detailed information available related to hospice margins. To better understand how costs vary along proposed hospice reimbursement models for factors such as for-profit status, provider status and case-mix, more detailed hospice margin data is needed. Though MedPAC and the GAO have calculated rough estimates of hospice margins, only detailed hospice margin data will allow new reimbursement models to be tested to a high degree of specificity.

A significant gap in the hospice literature exists for studies that evaluate other potential hospice payment systems. Additional research is needed to determine the strengths and weakness of these systems and they should include the assessment of the following:

- The level of administrative burden placed on CMS due to the complexity of the system. In the case of a diagnosis-specific flat rate payment system, CMS would be required to construct...
and monitor rates for each diagnosis category rather than one rate, which is characteristic of single payment system.

- The potential for system abuse. For example, if a case-mix based system was introduced, would there be a potential for diagnosis creep, similar to what is observed in the Home Health Prospective Payment System. The appropriateness of the system in the last week of life to cover costs.

6.1.3 Other Considerations

There are a number of other gaps in the hospice literature that should be considered.

- Hospice provider behavior of exceeding the cap limit is not well understood. Studies that have looked at this phenomenon are descriptive in nature and fail to fully describe how exceeding the cap limit fits in with a hospice provider’s overall operational strategy. Regardless, proposed reimbursement models must align payment incentive and cap limits.
- There is a lack of evidence on the effect of personal and provider preferences, as well as the interaction between the two, on the timing of hospice referral. Understanding how preferences impact referral would be useful when assessing potential effects of changes in reimbursement incentives.
- There is a gap in the hospice literature pertaining to the relationship between quality and different patterns of care. As stated in Section 4.1.2, the development of quality metrics for hospice care is especially challenging. However, if available, quality data from sources such as the FEHC should be merged with visit data to begin to assess the relationship between utilization and quality.
- There had been an inability to distinguish between discharges and revocations for hospice beneficiaries using claims data. In 2012, CMS resolved this issue by requiring hospice providers to use different condition codes to distinguish revocations from live discharges (CMS, 2012). However, a full set of data containing this distinction is not yet available for analysis. The ability to distinguish discharges from revocations would allow for a better assessment of whether patients are choosing to revoke hospice care or if providers are discharging patients in order to stay under their cap-limits. To capture this information, patients’ families could also be surveyed to determine whether they initiated the revocation process or if the hospice provider prompted them to do so.

6.1.4 Summary: Limitations

In summary, selection bias and generalizability are the primary limitations of the current hospice literature. Significant research gaps exist for economic studies that investigate hospice margins and evaluate potential payment models. These limitations should be taken into consideration and, when feasible, accounted for when reforming the hospice payment system.
7. Summary of Findings

This document is designed to provide an overview of current knowledge and trends related to characteristics of hospice enrollees, the hospice program, and hospice utilization. The goal is to inform stakeholders as it provides input on aspects of the hospice program considered to merit further examination and possible reform. A bulleted summary of each of the sections is presented below:

**Utilization, Access to Care and Impact on Medicare Costs:**

- Hospice access and utilization are increasing as evidenced by enrollment of an increasing percentage of Medicare patients across multiple diagnoses, an increasing number of hospice providers, and increasing availability of hospice in rural areas. While hospice usage has increased substantially over the past decade for all racial and ethnic groups, racial and ethnic differences in hospice use persist.
- The growth in the number of hospices over the past decade is mostly accounted for by the increase of for-profit hospices.
- Non-cancer diagnoses have not only experienced a growth in prevalence among the hospice population, but also account for a large increase in hospice length of stay. Non-cancer patients have less clearly defined survival trajectories than cancer patients, which makes determining the appropriate timing of hospice enrollment for these patients more difficult.
- Hospice care delivery in nursing homes has grown continuously since its introduction. Hospice patients in nursing homes generally are more likely to have a non-cancer diagnosis and to have longer stays. Nursing facility residents and assisted living facility patients received somewhat more hospice visits than patients cared for in a private home.
- Hospice enrollment is consistently higher among Medicare managed care (MMC) enrollees than those in fee-for-service (FFS). The current capitated payment method creates a financial incentive for MMC plans to enroll patients into hospice care. However, evidence does not indicate that MMC plans are inappropriately enrolling patients into hospice, and therefore differences in utilization are likely due to underuse in the FFS system rather than overuse in MMC.
- Research indicates that hospice care can generate savings to Medicare compared to conventional care, especially for patients with cancer diagnoses and with moderate lengths of stay. However, trends towards a growing percentage of hospice care for patients with non-cancer diagnoses may be leading to a reduction in the cost savings attributable to hospice.

**Costs, Payment Adequacy and Accuracy of Hospice Care:**

- The mix of services used to provide routine home care has changed over time: nursing, social services, pharmaceuticals, and medical equipment have increased, while home health aide services, supplies, and outpatient services decreased.
- Research conducted by RAND found that approximately 90% of the variation in resource use (number of visits and visit labor costs) could be explained by the number of days in each type of care (RHC, CHC, IRC and GIP), suggesting that hospice patients have similar care needs regardless of diagnoses and patient characteristics.
- Despite the persistence of very short hospice stays (less than seven days), the average length of stay for hospices has increased, driven by a rise in patients with non-cancer diagnoses.
This has resulted in higher profit margins for some hospices with more non-cancer patients, who tend to have longer stays and receive fewer visits per week from less skilled staff.

- In general, hospices that are above-cap, larger, freestanding, for-profit, and urban have higher profit margins than their counterparts.
- Smaller hospices and hospices in rural settings tend to have higher per diem costs and likely lower payments from Medicare, a combination that leaves these types of facilities at a financial disadvantage.
- Patient-specific visit data shows that hospice visits tend to be concentrated at the beginning and end of hospice stays; resulting in a U-shaped cost model, with the costs of care being higher at both the beginning and end of a hospice stay. This U-shaped pattern is consistent for both short and long lengths of stays.

**Payment System Vulnerabilities:**

- Over 80% of hospice claims reviewed did not meet at least one of Medicare’s mandatory requirements for provision of hospice care. Failure to meet the plan of care was the most common compliance concern.
- The ability to bill physician services to hospice patients under both Medicare Part A and Part B for hospices services makes the hospice program vulnerable to abuse by physicians and hospices.
- Hospices that exceeded the aggregate cap have substantially higher rates of live discharge than those not exceeding this cap. Patients discharged alive from hospice have longer hospice stays, are healthier at the time of enrollment, and require fewer resources during their time in hospice compared to other hospice patients, suggesting higher profit margins for these patients, and that some patients may have been admitted before they were terminally ill.
- The number of hospices exceeding the aggregate cap is increasing. Above-cap hospices are more likely to be for-profit, freestanding, urban, and have a smaller patient load. Patient case mix does not entirely explain a hospice’s proclivity to exceed the aggregate cap. Findings suggest that hospices exceeding the aggregate cap may preferentially enroll patients who are expected to live longer, and may be inappropriately enrolling patients who are not yet eligible for hospice care.
- Evidence suggests that Medicare may be paying twice for prescription drugs; once under the Hospice benefit per diem payment and again under Part D. When examining analgesics, anti-nausea, laxatives and anxiety prescription drugs, OIG found that these drugs were often being paid for by Medicare Part D, despite the fact that they probably should have been covered by hospices.

**Proposed Payment Refinements:**

- Several researchers have recommended an intensity-adjusted payment model that more accurately reflects the “U-shaped” resource use observed from hospice data analysis: higher payments at the beginning of the episode, relatively lower payments per day as length of stay increases, and relatively higher payments for the increased costs and utilization associated with the days preceding death. This type of reform would likely affect hospice providers in different ways (e.g., for-profit hospices, freestanding hospices, and hospices with a large proportion of long stays would likely face a decrease in payments whereas their counterparts would likely face an increase in payments).
• Researchers have examined using a case-mix adjustment for the hospice payment system, but have found that patient characteristics explain little of the variation in resource use.

• Payment refinements specific to hospice care provided in nursing homes have also been examined. In response to findings that hospice costs were lower for nursing home residents compared to non-resident hospice patients, researchers have recommended a downward adjustment to the hospice per diem rate for nursing home residents and for Medicare to consider modifying their benefit package to allow hospice services for beneficiaries who require skilled care in nursing homes. More significant departures from the current payment system have also been recommended for hospice care provided in nursing homes, such as a separate end-of-life Medicare benefit for nursing home residents where nursing homes would be paid directly for hospice services and held accountable for providing high quality end-of-life care.

• Hospice organizational characteristics, patterns of care delivery, and site of care may also be important considerations in payment reform, and additional research is needed to understand the implications of accounting for these differences in refinement to the hospice payment system.
8. Acknowledgements

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9. References

References preceded by an asterisk are not included in the text but aided in our understanding of the literature.


Emanuel, E. J., Ash, A., Yu, W., Gazelle, G., Levinsky, N. G., Saynina, O. et al. (2002). Managed care, hospice use, site of death, and medical expenditures in the last year of life. Archives of Internal Medicine, 162, 1722-1728.


Federal Register (2008a). Medicare and Medicaid programs; Hospice conditions of participation; final rule. Federal Register, 73, 32088-32220.


Han, B., Remsburg, R. E., & Iwashyna, T. J. (2006). Differences in hospice use between black and white patients during the period 1992 through 2000. Medical Care, 44, 731-737.


Teno, J.M., Casarett, D., Spence, C., Connor S. (2012). It is “too late” or is it? Bereaved family member perception of hospice referral when their family member was on hospice for seven days or less. *Journal of Pain and Symptom Management*, 43, 732-738.


### Appendix A: Search Terms for Literature Review Screening

<table>
<thead>
<tr>
<th>Search Terms</th>
<th>Number of Articles Found</th>
<th>Number of Articles Cited a</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospice and utilization</td>
<td>498</td>
<td>28</td>
</tr>
<tr>
<td>Hospice and payment</td>
<td>83</td>
<td>9</td>
</tr>
<tr>
<td>Hospice and cost</td>
<td>668</td>
<td>15</td>
</tr>
<tr>
<td>Hospice and geographic variation</td>
<td>10</td>
<td>1</td>
</tr>
<tr>
<td>Hospice and &quot;site of death&quot;</td>
<td>39</td>
<td>1</td>
</tr>
<tr>
<td>Hospice and &quot;nursing home&quot;</td>
<td>206</td>
<td>13</td>
</tr>
<tr>
<td>Hospice and &quot;assisted living&quot;</td>
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<td>0</td>
</tr>
<tr>
<td>Hospice and (disenroll or revoke)</td>
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<td>3</td>
</tr>
<tr>
<td>Hospice and Medicare</td>
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<td>35</td>
</tr>
<tr>
<td>Hospice and ethnicity</td>
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<tr>
<td>Sum of combined searches b</td>
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<tr>
<td>Total unique publications c</td>
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</tr>
<tr>
<td>Additional non-peer reviewed materials d</td>
<td>45 e</td>
<td>31</td>
</tr>
<tr>
<td>Additional articles identified</td>
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<td>58</td>
</tr>
</tbody>
</table>

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a The bibliographic search yielded numerous publications that were of marginal relevance as well as publications that were duplicative in content. All sources searched were screened using a tiered approach. First, article title content was reviewed to eliminate articles that were obviously not related to the research questions of interest, such as pharmacological studies. Second, abstracts were reviewed to determine if the methodology appeared to be sound and findings were relevant and significant. Publications meeting these criteria were subjected to further (full text) content review for potential inclusion in the final list of sources for this review.

b All searches conducted during late 2010 and early 2011, not necessarily on the same day. If all searches were conducted simultaneously, results would differ.

c Unique publications based on a single search with hospice search term AND any of the other search terms. Search conducted after other searches, so it may include some articles added to the database after previous searches.

d This includes reports from MedPAC, OIG, GAO, and NHPCO; CMS publications and transmittals; the Federal Register and federal laws; and relevant websites.

e Approximate count.