1. Background

In 2012, the Abt team conducted a comprehensive review of existing literature on topics related to hospice payment reform. In mid-2014 and mid-2015, the team provided annual updates to this review covering the period of December 2, 2012 to December 31, 2014. This document updates these literature reviews by identifying and reviewing additional scholarly articles published between January 1, 2015 and December 31, 2015.

2. Methodology

This review includes peer-reviewed English language journal articles and select reports by the Medicare Payment Advisory Committee (MedPAC), U.S. Government Accountability Office (GAO), and the Health and Human Services (HHS) Office of the Inspector General (OIG) published between January 1, 2015 and December 31, 2015.

To ensure continuity, the team utilized the same database as in previous reviews (PubMed), searched using the same terms and phrases, and applied the same exclusion criteria to articles as it had previously done for prior reviews. Search terms and information on articles found and cited are shown in the table below.
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.

For a comprehensive list of search terms and discussion of the parameters applied when excluding articles, please see the initial literature review from 2012.
3. Findings

The team found that hospice utilization continues to increase overall, though racial and ethnic minorities continue to access hospice less than their white counterparts. Provider characteristics, particularly providers’ clinical experience with and training in end-of-life care, continue to impact hospice enrollment levels, and hospice beneficiaries’ care trajectories. Site of service similarly continues to shape hospice use, particularly among beneficiaries using hospice at nursing homes and assisted living facilities. Care planning and coordination remains associated with timelier referral to and enrollment in the hospice benefit, and enrollment in hospice continues to be linked to significant reductions in non-hospice care costs and service use.

3.1 Changes in the Hospice Provider Market

The total number of available hospice providers continues to increase, with MedPAC reporting a 5% increase in the overall provider pool in 2013 (n = 3,925). For-profit providers continue to enter the market at higher rates than not-for-profit providers, with a 9.6% increase in total market share in 2013. Freestanding hospices continue to dominate the market as a whole—73% of 2013 hospice providers were freestanding hospices—while the number of hospital-based hospices has declined slightly. New entrants appear concentrated in California and Texas, which collectively accounted for 60% of the 2013 increase in hospice providers.

3.2 Variations in Hospice Utilization over Time

Hospice enrollment among individuals with terminal illness continues to expand. Gozalo, Plotzke and colleagues, for example, conducted a propensity-matched, difference-in-difference analysis using Medicare Minimum Data Set (MDS) and claims data from 786,328 nursing home-based decedents enrolled in hospice in 2004 and 2009, and found an increase in overall enrollment. A retrospective review of Medicare claims and the Surveillance, Epidemiology, and End Results (SEER) cancer registry data similarly examined hospice and end-of-life healthcare utilization by 816 patients treated for metastatic melanoma between 2000 and 2007, and noted that hospice use increased sizably over the seven-year period (from 61% to 79%), though “increased enrollment was more drastic and spiked early for patients” enrolled in hospice for three days or less, where longer-term hospice use (i.e., enrollment for four days or more) increased steadily over time. Analyses of the Agency for Healthcare Research and Quality’s (AHRQ’s) Nationwide Inpatient Sample (NIS) data for 100,220 patients hospitalized for metastatic prostate cancer between 1998 and 2010 similarly found a marked increase in hospice use of 488% per year in this patient population over the 12-year period. An examination of Medicare and Veterans Health Administration (VA) data for approximately 19,000 veteran decedents treated for cancer between 2006 and 2012...
also noted that the proportion of veterans utilizing hospice care increased from 55 to 68% during that time period, though median time between hospice election and death remained stable.\

Costs defrayed by enrolling in hospice remain unclear, though researchers caution that increased enrollment and shifting beneficiary demographics may contribute to disparate cost trajectories. Gozalo et al’s study reported a net increase of $6,761 in Medicare expenditures per decedent in the last year of life, but indicated that increased expenditures could be attributed in part to an increase in beneficiaries’ average length-of-stay in hospice as well as an increase in the proportion of beneficiaries with non-cancer primary hospice-diagnoses. Despite the increase in costs, the study did find a reduction in delivery of aggressive end-of-life care among hospice enrollees. Sammon and colleagues hypothesized that the dramatic increase in hospice use among decedents in his study’s sample helped mitigate increased per-incident hospitalization costs and “stabilize” those decedents’ overall economic burden of care.

### 3.3 Variations in Utilization by Provider Characteristics

Provider characteristics impact Medicare beneficiaries’ enrollment in hospice according to an analysis of 198,948 Medicaid fee-for-service (FFS) beneficiaries with a poor prognosis cancer who died between 2006 and 2011. This study determined that the proportion of a physician’s patients already enrolled in hospice was a strong predictor of whether or not the physician’s other patients would later enroll in hospice; and that decedents treated by medical oncologists and those receiving care at not-for-profit hospitals were also significantly more likely to enroll in the benefit. Similarly, a survey of 239 neuro-oncology care clinicians determined that clinicians’ female gender, formal training in palliative care, and medical (versus surgical) neuro-oncology training were significantly associated with reported use of hospice referral when treating patients with glioblastoma.

Specialized training in the patient’s primary hospice diagnosis may also impact a provider’s decision to enroll an individual in hospice care. Safarpour and colleagues examined 2002 Medicare data for 469,055 beneficiaries with Parkinson disease and discovered that, among those residing in long-term care facilities, individuals who were treated by an outpatient neurologist were more than twice as likely to receive hospice care before death, even after controlling for other factors like disease severity and comorbidity. A small-scale review of electronic health record (EHR) data for 179 decedents treated at a Maryland medical center over a one-year period similarly found that patients whose care was managed by an oncologist reported higher rates of hospice use, and lower rates of hospitalization and intensive care unit (ICU) stays in the last 30 days of life.
3.4 Variations in Utilization by Beneficiary Characteristics

3.4.1 Race and Ethnicity

Racial and ethnic minorities continue to enroll in hospice at lower rates than their white peers. An examination of end-of-life spending among 37,393 lung cancer decedents (as documented in Medicare data and SEER cancer registries) found that, even after controlling for confounding factors, use of hospice care was higher among whites than other ethnic populations, and mean total health care costs were significantly higher for blacks and other ethnic minorities when compared to whites, “regardless of length of survival time or hospice care status,” suggesting that racial/ethnic disparities exist in end-of-life care for individuals with terminal lung cancer.\(^\text{18}\) Another analysis of Medicare, SEER, and Indian Health Service Care System data for 76,259 patients with breast, colorectal, lung, prostate, ovarian, and stomach cancer found that American Indian and Alaska Native patients utilized hospice care at a significantly lower rate than their non-Hispanic white counterparts, even after controlling for sociodemographic factors (e.g., income level, urban residence, and age) known to influence hospice use.\(^\text{19}\) Similar analyses of Medicare and SEER data for 7,383 patients with oral cavity or pharyngeal cancer found that individuals who enrolled in hospice were more likely to be white.\(^\text{20}\) Sammon and colleagues’ analyses of AHRQ NIS data similarly noted that, though hospice use increased among all metastatic prostate cancer patients “followed” from 1998 to 2010, hospice uptake among black and Hispanic patients remained significantly lower than that of white patients with similar diagnoses.\(^\text{21}\)

Racial and ethnic minorities receiving end-of-life care were less likely to have advanced care planning documentation (e.g., a designated power of attorney, do not resuscitate (DNR) order, or a living will) in place, even after enrolling in hospice according to two studies. Frahm and colleagues discovered that, among 88,426 long-stay nursing home residents who received hospice care in 2007, black, Hispanic, and Asian residents were significantly less likely to have a designated power of attorney for health care, living will, and DNR order documented in their MDS records.\(^\text{22}\) These racial and ethnic minorities were also significantly more likely to be hospitalized while receiving hospice than their white counterparts, and significantly less likely to die while enrolled in the benefit.\(^\text{23}\) A smaller-scale review of medical records for 189 decedents treated at the University of Texas MD Anderson Cancer Center for advanced gynecologic cancer similarly found that non-white patients were both significantly more likely to report dying without hospice, and significantly more likely to report not having a designated power of attorney or living will in place, even after enrollment into hospice care, suggesting that “hospice enrollment did not increase advance directive completion among minority” patients.\(^\text{24}\)

One study, however, suggested that African American patients were more likely to enroll in the hospice benefit; Colón and Lyke reviewed archival data for 2,625 individuals treated at a single community-based hospice over a six-year period, and found that African-American
patients were, in fact, more likely to enroll in hospice than individuals of European American, Latino and Asian descent. 25 Latino patients were found to be less likely to use hospice than other ethnic groups.

Survey research examining racial and ethnic minorities’ understanding of hospice services reported that racial and ethnic minorities reported less familiarity with the benefit, even after controlling for other factors. Carrion and colleagues conducted a small-scale survey of 123 Americans to ascertain their knowledge and attitudes about hospice care, and found that Hispanics were less likely to have heard of hospice care and more likely to report inaccurate information about the benefit. Similarily, a survey of 604 community-dwelling Asian and Hispanic adults in Queens County, New York, found that familiarity with hospice services varied significantly across ethnic groups, with Hispanic respondents reporting less familiarity and Korean and Chinese respondents reporting more familiarity with hospice care.

3.4.2 Urban/rural location

One study identified disparities in hospice service use among urban and rural Medicare beneficiaries. Wang and colleagues reviewed Medicare claims data for 175,181 elderly decedents with a poor-prognosis cancer and noted that rural Medicare beneficiaries were less likely to use hospice and home health services than “similar” beneficiaries residing in urban areas, and more likely to use outpatient and skilled nursing facility (SNF) services than urban-dwelling decedents. Rural beneficiaries also reportedly cost Medicare approximately 4-10% less in their last year of life compared to urban beneficiaries.

3.4.3 Pre-hospice morbidity

Referral to hospice remains underutilized for individuals hospitalized at the end of life. A retrospective study of Medicare MDS and claims data from 2000 to 2007 evaluated the frequency of referral to hospice among nursing home decedents with advanced dementia who required inpatient psychiatric treatment in the last 90 days of life, and found that less than 10% of those decedents were referred to hospice after their hospital stay. Similarly, a review of Medicare claims and EHR data for 8,555 enrollees in the Alabama Heart Failure Project between 1998 and 2001, examined the frequency of referral to hospice among those hospitalized for heart failure, and found that less than 2% received hospice discharge referrals despite the fact that 20% of those discharged without a referral ultimately died within six months post-discharge. Patients who did receive a referral documented significantly lower 30-day all-cause readmission rates.

3.4.4 Pre-hospice insurance type

Insurance type prior to hospice enrollment was also found to impact hospice enrollment in at least one study; a research team at the University of Texas MD Anderson Cancer Center analyzed Texas Cancer Registry data for Medicaid and Medicaid beneficiaries with terminal cancer treated between 2000 and 2008, and determined that Medicaid recipients were
significantly less likely to enroll in hospice in their last 30 days of life, and individuals
dually-eligible for both Medicare and Medicaid were most likely to enroll in the benefit, even
after controlling for other factors.33

### 3.5 Variations in Utilization by Hospice Diagnosis

_Beneficiaries’ primary hospice diagnoses continue to shape care trajectories and lengths of stay._ Analyses of EHR data for 48,147 patients treated at 10 U.S. hospices participating in the Coalition of Hospices Organized to Investigate Comparative Effectiveness (CHOICE) care network found that—though they represented only 7.3% of patients sampled—individuals with hematologic malignancies (e.g., leukemia) were significantly more likely to die within 24 hours of hospice enrollment, or within the first seven days on the benefit, when compared to hospice enrollees with solid tumors.34 Those with hematologic malignancies were also significantly more likely to receive hospice care in an inpatient or nursing home setting.35

**Pain management strategies** for and subsequent reductions in reported pain amongst hospice beneficiaries also appear to _vary by primary hospice diagnosis_; in reviewing medical records for 146 patients with end-stage dementia, chronic obstructive pulmonary disease (COPD), and cancer who reported receiving inpatient hospice care in 2011 and 2012, Romem and colleagues found that “admission diagnosis [was] the strongest predictor of [reported] pain control.”36 Although more than 90% of patients sampled reported experiencing clinically significant pain at the time of enrollment to hospice, less than 50% of those with COPD and cancer reported achieving adequate pain control within 24 hours of admission.37 By contrast, end-stage dementia patients were more likely to report achieving pain control.38

### 3.6 Variations in Utilization by Site of Service

A beneficiary’s residence in an assisted living facility (ALF) can impact the timing and
duration of his/her hospice enrollment. Analyses of EHR data for 85,581 patients treated at
12 U.S. hospices participating in the CHOICE care network determined that individuals
receiving hospice care while residing in an ALF tended to enroll in the benefit earlier than
those who enrolled while living at home, and were more likely to remain in their residence
until their death.39 ALF-based hospice care was associated with older age, white race, and
not having a spouse. Median length of stay for ALF-based beneficiaries was shorter (24
days) than those receiving care at home (29 days), though their mean length of stay (96 days)
was considerably longer than their home-based peers (78 days), suggesting that very long-
stay outliers may exist in the ALF-based hospice beneficiary population.40

Hospice penetration in a beneficiary’s immediate health care service area can also impact
his/her likelihood of enrolling in the benefit. A retrospective review of approximately 2
million hospitalization episodes reported by Medicare beneficiaries nationally between 2005
and 2009 found that “area-level hospice utilization was inversely proportional to rehospitalization rates.”41 In stratifying hospice use and hospitalization data by Hospital Service Area (HSA), the researchers found that beneficiaries residing in areas with higher hospice use rates also reported higher rates of dying while enrolled in the benefit, and that those who resided in HSAs with lower hospice use rates were less likely to report dying on the benefit, and more likely to report re-hospitalization over a 30-day period.42

### 3.7 Variations in Utilization by Characteristics of Care Provision

_Care planning for terminally ill individuals continues to be associated with increased enrollment in and use of hospice._ A small-scale study examining the impact of implementing goals of care meetings for patients with advanced cancer diagnoses found that those for whom meetings were held were less likely to receive critical care interventions and more likely to be discharged to hospice.43 Similarly, a retrospective review of medical records for 65 patients with end-stage renal disease (ESRD) on dialysis who died between 2008 and 2012 found that “advance care planning was associated with a low incidence of in-hospital death and among those who withdrew, a high use of hospice.”44 Zakhour and colleagues likewise evaluated the impact of end-of-life (EOL) discussions on hospice enrollment and “aggressive” care interventions in the final days of life among women with terminal gynecologic malignancies, and found that those who reported earlier EOL discussions were more likely to be enrolled in hospice at the time of death and spend more days on the benefit.45

Receipt of continuous care in the final days of life has been linked to decreased likelihood of death in an inpatient hospice setting, and decreased likelihood of live discharge. An examination of EHR data for 147,137 patients treated at 11 U.S. hospices participating in the CHOICE care network found that continuous home care was received by only 10.2% of individuals on the day prior to death. Though a small percentage overall, patients who received continuous care the day prior to death were significantly less likely to die in an inpatient hospice setting, with greater reductions in inpatient deaths reported among those being cared for by a spouse or living at home. Additionally, among the study’s 147,137 patient cases, less than one percent of those discharged alive reported having received continuous care on the day before discharge.46

In one trial, prior and concurrent provision of palliative care services was associated with increased use of hospice and decreased costs at the end of life. Researchers at the University of Virginia reported a connection between “phased” palliative care treatment and hospice use. The university’s Comprehensive Assessment with Rapid Evaluation and Treatment (CARE Track) program followed 207 patients with advanced cancer over a year, and compared their service use to 198 patients treated by the university’s cancer center (but not enrolled in the CARE intervention), and found that those who received stepped palliative...
care documented increased hospice utilization and decreased overall costs of care in the final three months of life.  

3.8 Impact of Hospice Use on Non-Hospice Care Utilization and Costs

Some researchers continue to find that hospice use is associated with decreased use of non-hospice care services, and decreased non-hospice care costs. Huo and colleagues analyses of hospice service use by patients with metastatic melanoma noted significant reductions in use of chemotherapy, surgery, and radiation therapy among those who enrolled in hospice for four days or more. A retrospective review of Medicare claims and the SEER cancer registry data examined hospice and end-of-life care utilization by 7,383 decedents treated for oral cavity or pharyngeal cancer between 1995 and 2007, and found that enrollment in hospice was associated with significant reductions in all-cause Medicare expenditures in the last month of life ($7,035 for individuals with oral cavity cancer, and $7,430 for individuals with pharyngeal cancer), and that savings were greater among those enrolled in hospice for 30 days or more at the time of their death. An examination of service use among 433,063 Medicare fee-for-service decedents with Alzheimer’s disease or related dementias (ADRD), heart failure, stroke or transient ischemic attack, lung cancer, and colorectal cancer found that hospice enrollment for periods of two weeks or more was associated with decreased hospital use across all diagnostic groups, and decreased Medicare spending of $900-$5,000 for beneficiaries enrolled in hospice for 31-90 days, excluding those enrolled in nursing homes and/or those with ADRD.

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5 Ibid.
6 Ibid.
7 Ibid.

12 Gozalo et al. (2015).

13 Sammon et al. (2015).


21 Sammon et al. (2015).


23 Ibid.


29 Ibid.


32 Ibid.


35 Ibid.
37 Ibid.
38 Ibid.
40 Ibid.
42 Ibid.