June 28, 2013

Marilyn Tavenner, Administrator
Centers for Medicare & Medicaid Services
Department of Health and Human Services
Attention: CMS–1449–P
P.O. Box 8010
Baltimore, MD 21244–8010

Dear Administrator Tavenner,

The National Hospice and Palliative Care Organization (NHPCO) is pleased to provide comments on the CMS 1449–P, Medicare Program; FY 2014 Hospice Wage Index and Payment Rate Update; Hospice Quality Reporting Requirements; and Updates on Payment Reform, published in the Federal Register on May 10, 2013. In preparing these comments, NHPCO conducted “listening sessions” with over 1,100 hospice providers to get their feedback, comments and concerns about the proposed rule. These comments reflect those discussions, as well as numerous discussions with hospice CEOs, physicians, nurses, social workers, spiritual counselors, software vendors and other stakeholders.

NHPCO is the largest membership organization in the country representing the entire spectrum of not for profit and for profit hospice and palliative care programs and professionals in the United States. We represent over 3,500 hospice locations and more than 44,000 hospice professionals in the United States, caring for the vast majority of the nation’s hospice patients. The organization is committed to improving end-of-life care and expanding access to hospice care with the goal of creating an environment in which individuals and families facing serious illness, death, and grief will experience the best that humankind can offer.

We appreciate the opportunity to comment on the following proposals and clarifications put forth by CMS, and on the update regarding CMS’s activities and current thinking related to hospice payment reform. As always, NHPCO looks forward to working collaboratively with CMS to help insure that all Medicare beneficiaries and their families continue to have access to high quality hospice services at the end of life.
A. Diagnosis Reporting on Hospice Claims

NHPCO is pleased to provide comments on coding for hospice diagnoses using the ICD-9-CM coding guidelines. Hospice physicians are responsible for making a clinical determination of the best diagnosis for an individual patient. Coders and other hospice professionals work to identify diagnosis codes for the purposes of filing claims for reimbursement, while complying with the various requirements from CMS and working within the parameters of current electronic medical record and billing software. Our comments have been separated into sections, including overall comments on hospice coding and coding resources, related and unrelated diagnoses and the role of the hospice physician and community attending physician.

1. ICD-9-CM Coding Guidelines

From the proposed rule: We clarified in our July 27, 2012 FY 2013 Hospice Wage Index notice (77 FR 44247 through 44248) that all providers should code and report the principal diagnosis as well as all coexisting and additional diagnoses related to the terminal condition or related conditions to more fully describe the Medicare patients they are treating.

Challenges with Hospice Coding

Beneficiaries admitted to hospice often have multiple chronic or co-morbid conditions, some of which contribute to the patient’s six month prognosis. As a result, it is often quite difficult for a hospice physician to properly assign the correct principal diagnosis and, at the same time, follow the ICD-9-CM guidelines. The Medicare hospice benefit was established with the focus on prognosis, rather than diagnosis. Many hospices have reported only one primary terminal diagnosis on the claim form, based on directives from their Medicare Administrative Contractors (MACs) and software limitations. When information was published in the FY2013 Hospice Wage Index Notice regarding reporting of multiple diagnoses on the claim form, hospice software vendors began the task of adjusting billing software to allow multiple diagnoses on the claim form, and that process continues.

Hospice Coding Resources

As NHPCO consulted with our members to begin the preparation of comments for this proposed rule, hospice staff pulled out their coding reference books, published by different companies, which they have been using for coding purposes. Hospice providers have been unsure about the appropriateness of using available coding
resources that specifically target the home care setting, or the non-inpatient setting. Hospice providers generally have followed the guidance on diagnoses provided by MACs, including LCDs supporting the reporting of “adult failure to thrive” and “debility” as diagnoses for hospice patients. At least one of the published ICD-9-CM coding manuals endorses the use of particular codes for hospice patients and includes symbols to identify these diagnoses, including “adult failure to thrive” and “debility”.

We are unaware of current resources on coding that will assist hospice providers with coding hospice claims properly. NHPCO and other hospice organizations are committed to providing coding education for hospice physicians and for other hospice staff and to working collaboratively with CMS to ensure that coding guidelines and hospice regulatory requirements are not in conflict.

Coding Language

In previous CMS transmittals, including the FY2013 Wage Index Notice, the words “related, non-related, co-existing, and secondary conditions” have all been used interchangeably to describe “other diagnoses.” Providers have also received confusing language from the MACs, who, in addition to the above language, also include the phrase “co-morbid conditions.” To promote consistency among hospice providers, and in keeping with the coding manual, NHPCO requests dialogue with CMS to increase clarity about the language used to refer to diagnoses in keeping with the language used in the ICD-9-CM coding manual.

2. Related and Unrelated Diagnoses

NHPCO summarizes below our comments on determining relatedness, including the process used by the hospice physician to determine the diagnosis(es) that contribute to the patient’s terminal prognosis and the role of the patient’s attending physician.

From the proposed rule: We also discussed related versus unrelated diagnosis reporting on claims and clarified that “all of a patient’s coexisting or additional diagnoses” related to the terminal illness or related conditions should be reported on the hospice claims... For beneficiaries eligible for the Medicare hospice benefit, access to hospice care or the continuation of hospice care should not be affected or limited by the following ICD–9–CM coding guidelines for diagnosis reporting on claims... We are restating what we communicated in the December 16, 1983 Hospice final rule regarding what is related versus unrelated to the terminal illness: “. . . we believe that the unique physical
condition of each terminally ill individual makes it necessary for these decisions to be made on a case–by-case basis. It is our general view that . . . “hospices are required to provide virtually all the care that is needed by terminally ill patients” (48 FR 56010 through 56011). Therefore, unless there is clear evidence that a condition is unrelated to the terminal illness, all services would be considered related. It is also the responsibility of the hospice physician to document why a patient’s medical need(s) would be unrelated to the terminal illness.

The hospice physician is responsible for determining the diagnosis(es) that is the most likely cause of the patient’s terminal prognosis. In some cases, a single diagnosis, e.g., pancreatic cancer, accurately describes the basis for that prognosis. In others, there may be related diagnoses, e.g., Alzheimer's dementia and aspiration pneumonia. Finally, there are some cases in which multiple prognosis-determining diagnoses combine to give the patient a prognosis of less than 6 months, e.g., ischemic cardiomyopathy and chronic obstructive pulmonary disease. However, many patients admitted to hospice also have been diagnosed with, and continue treatment for, other conditions that are unrelated to their terminal condition. We strongly disagree with the suggestion that hospices are required to provide virtually all the care needed by terminally ill patients, even if that care has no relationship to the patient’s terminal prognosis.

Again, eligibility for the Medicare Hospice Benefit is not determined by the diagnosis but by the prognosis, which is influenced by patient factors such as age, functional status, symptoms, and degree of frailty, among others. Prognostication requires medical judgment that involves more than assigning ICD-9-CM codes. In determining prognosis, the number of diagnoses does not correlate well with the acuity of the patient and family needs or the expected trajectory of the patient’s condition.

Additionally, the Medicare Hospice Benefit exclusively covers palliative therapies. Many treatments available to terminally ill Medicare beneficiaries have little or no palliative benefit. Although some therapies may be palliative and could be used by patients earlier in their disease process, by the time the patient is admitted to hospice, many of these therapies have little or no benefit. The hospice physician is responsible for assessing and determining the palliative benefit of a given therapy, taking into account the patient’s prognosis and functional status, as well as the benefits and burdens of treatment. The following questions guide the decision to provide or not to provide a particular treatment under the Medicare Hospice Benefit.
1. Is the treatment related to the terminal diagnosis and related conditions?
2. Does it have palliative benefit based upon the patient’s current condition and is it part of the hospice plan of care?

As CMS considers the information gathered on multiple diagnoses from the claim form, NHPCO strongly believes that the presence of symptoms and stage of illness are far more important factors in the complexity of care and determination of prognosis than the number of diagnoses reported. In the experience of hospice and palliative care health care professionals, a higher number of diagnoses does not necessarily indicate higher acuity, nor does the quantity of diagnoses indicate the quality of care being provided.

Role of Hospice Physician and the Community Attending Physician

Hospice physicians have both a primary role and a responsibility in determining relatedness to the terminal illness and have commented that what might be related a few days before death is different than what is related 3-6 months before death. Ongoing assessment of hospice eligibility is a process, not an event, and the plan of care, specifying what services are to be provided, changes over time. In the initial certification of terminal illness, both the hospice physician and the community attending physician collaborate to attest that the prognosis estimate makes the patient eligible for the Medicare Hospice Benefit. In ongoing care, determinations about relatedness change, based on changing goals of care, the disease process, changes in patient condition, and indications for and efficacy of the therapies. As the patient’s condition changes, the medical conditions related to the terminal diagnosis may change. The hospice physician’s role and responsibility remains central to the care and services that hospice professionals provide.

We agree with CMS that the “unique physical condition of each terminally ill individual makes it necessary for these decisions to be made on a case-by-case basis, and we believe this must be determined by the physician(s) based on their best medical judgment.” However, the suggestion by CMS that “hospices are required to provide virtually all the care that is needed by terminally ill patients” is not supported either by the hospice statute or regulations and is an inappropriate standard. The Medicare statute and the Medicare hospice regulations both require hospices to cover services that are reasonable and necessary for the palliation and management of the beneficiary’s terminal illness as well as related conditions. Many patients enter hospice
with multiple medical conditions, some of which may be completely unrelated to their hospice eligibility. Below is just one case example illustrating this point.

**Case Example:** A 78 year old man with a long history of multiple medical problems was diagnosed with cholangiocarcinoma three months before admission to hospice. A biliary stent had been placed for the biliary obstruction. After discussion with the oncologist about the risks and benefits of chemotherapy, he opted not to have chemotherapy. The oncologist estimated his prognosis to be 3-6 months.

He had a history of hypothyroidism for which he was on thyroid hormone, hypertension for which he was on a diuretic, a beta blocker, and an ace inhibitor, diabetes for which he was on insulin and an oral agent, and a seizure disorder for which he was on 2 anticonvulsants.

This is a patient with four distinct unrelated medical problems for which he was taking 8 medications. None of these diagnoses or medications was related to his terminal illness, cholangiocarcinoma, which was the basis for his hospice admission. The medications did, however, provide appropriate treatment for these conditions and helped to maintain his quality of life and were continued. Having a terminal illness did not negate the need to provide quality care of co-existing problems, which were not covered by the hospice provider.

3. **Use of Nonspecific, Symptom Diagnoses**

NHPCO has spoken with many hospice physicians and providers who have read the proposed rule and have focused on this section. While some hospices may be over-using “debility” and “adult failure to thrive” as the primary hospice diagnosis when other, more specific, diagnoses may be more appropriate, there are some patients for whom these diagnoses are appropriate and we urge CMS to allow their continuation. In cases where “debility” or “adult failure to thrive” is the best description of the patient’s terminal condition, the hospice provider absolutely continues to develop and implement a comprehensive, individualized plan of care for the patient, to guide the care and services provided.

The sections below provide additional detail on various sections of the proposed rule and include case examples that illustrate the challenges with identifying appropriate diagnoses for some hospice patients.

**Adult Failure to Thrive and Debility**
From the proposed rule: “Adult Failure to Thrive” is often used interchangeably with “debility” as a primary hospice diagnosis. Despite the specificity of ICD–9–CM Coding Guidelines, it is unclear as to why these two diagnoses are often used interchangeably. A reported principal hospice diagnosis in the nonspecific ICD–9–CM category, “Symptoms, Signs, and Ill-Defined Conditions”, such as “debility” or “adult failure to thrive,” does not encompass the comprehensive, holistic nature of the assessment and care to be provided under the Medicare hospice benefit.

NHPCO is concerned that hospice providers who have focused on diagnoses of “debility” and “adult failure to thrive” are now looking for other non-specific diagnoses in the 780-799 coding section, (e.g. cachexia, abnormal weight loss, etc.) as acceptable substitutes. We believe the intent of the proposed rule is to address the use of 780-799 coding as the primary diagnosis and their appropriate use as a primary diagnosis. However, we are concerned that numerous references to “debility” and “adult failure to thrive” may have distracted providers from this larger issue or selected more specific diagnosis codes when appropriate.

Nonspecific diagnoses are generally chosen when a patient does not meet the Local Coverage Determination (LCD) guidelines for a more specific diagnosis but has been determined to have a 6 month prognosis. The MACs have not previously discouraged these diagnostic options; in fact, Palmetto GBA has a specific LCD for “adult failure to thrive,” which encompasses Failure to Thrive, Debility unspecified, Other Ill-Defined Conditions and Other unknown and unspecified causes of morbidity or mortality. NO diagnosis alone determines or describes the assessment or care to be provided on an on-going basis by the hospice. In addition, the use of a non-specific diagnosis has no effect on the "holistic nature of the assessment and care" provided by the hospice. The following case example illustrates the issues surrounding “adult failure to thrive” as an appropriate terminal diagnosis:

**Case example:**
JR was the oldest patient I ever cared for. She had history of remote colon cancer (surgically cured when she was 95), which is when she entered the nursing home under my care. After recovering from her surgery, her medical conditions consisted of osteoarthritis (moderate) and mild cognitive impairment. Several months before her 107th birthday, she began to lose weight and in a six week period, experienced a 20 pound weight loss. Her oral intake was significantly decreased, and the hospice team attempted to improve nutritional intake without success. She also became functionally more debilitated, with significantly increased need for assistance with activities of daily living. She stated that her arthritis was no worse, and no other new problems were identified. She declined any major diagnostic
Laboratory showed very mild anemia, but there was no evidence of recurrence of her cancer. Efforts to improve nutrition and function were unsuccessful. Over the next few months, her BMI fell to 17 and her PPS declined to 30%. The hospice team provided comfort and support for a natural death and provided counseling to the family. There was no more specific diagnosis identified than “adult failure to thrive,” and she easily met the criteria for the Palmetto LCD. She was admitted to hospice with this diagnosis and died ten weeks later after a progressive course, during which time no other diagnoses were ever identified. “Adult Failure to Thrive” was the diagnosis entered on her death certificate.

Furthermore, the official ICD-9-CM coding guidelines also support use of nonspecific or symptom coding, and this concept is repeated throughout the guidelines found in the ICD-9-CM coding manual. A few examples include:

- “Codes that describe symptoms and signs, as opposed to diagnoses, are acceptable for reporting purposes when a related definitive diagnosis has not been established by the provider.”
- “Additional signs and symptoms that may not be associated routinely with a disease process should be coded when present.”
- And, finally, “Codes that describe symptoms and signs as opposed to diagnoses, are acceptable for reporting purposes when a diagnosis has not been established (confirmed) by the provider.”

NHPCO respectfully requests reconsideration of the use of “debility” and “adult failure to thrive” as diagnoses for a small subset of patients who are clearly exhibiting decline, are hospice appropriate, and for whom the diagnosis is appropriate. This also is consistent with the official ICD-9-CM coding guidelines. NHPCO will be pleased to collaborate with CMS on guidelines for the correct use of these codes as a primary diagnosis and to provide education to providers on the use of these codes and more specific codes, as appropriate for a given patient.

**Ill-defined Diagnoses and Comprehensive Assessment and Plan of Care**

From the proposed rule: If a nonspecific, ill-defined diagnosis is reported as the principal hospice diagnosis, a comprehensive, individualized patient-centered plan of care, as

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required, may be difficult to accurately develop and implement, and, as a result, the hospice beneficiary may not receive the full benefit of hospice services.

NHPCO strongly disagrees with CMS’s conclusion. This comment in the proposed rule makes the assumption that the hospice team would not be conducting an initial and comprehensive assessment of the patient, or developing and regularly updating an individualized plan of care if a patient has a nonspecific or ill-defined diagnosis. That is emphatically not the case. In hospice practice, if a nonspecific, ill-defined diagnosis is listed as the principal hospice diagnosis, it is often because the team has conducted an initial and comprehensive assessment and cannot determine which of many co-morbid conditions would be most likely to cause the patient’s death.

Only when there is no clear determination of a more specific primary diagnosis would a nonspecific diagnosis be used. Often, the hospice physician may suspect that there is some new underlying disease that would require additional testing in order to determine an accurate diagnosis. But patients and their families have the option to decline further diagnostic testing, and it is not unusual for them to do so when the patient is already frail and elderly, and the hospice will honor the patient’s wishes. And, as stated elsewhere within these comments, correct coding does not permit assigning an ICD-9-CM code to a condition that is suspected but not confirmed.

When a Related Definitive Diagnosis has not been Established

The ICD-9-CM Coding Manual states:

A. Codes for symptoms, signs, and ill-defined conditions. Codes for symptoms, signs, and ill-defined conditions from Chapter 16 are not to be used as principal diagnosis when a related definitive diagnosis has been established.  

Given the clear guidance in the ICD-9-CM Coding Manual, CMS should consider alternatives to the RTP process for these diagnoses. The role and responsibility of the hospice physician to use their best clinical judgment for making diagnosis decisions should be respected. A case example will illustrate the complexity of this issue:

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**Case example:** This 100 year old female was admitted to our hospice program at home in OCT 2012. She was very hard of hearing, blind in the right eye and had limited vision in the left eye but otherwise had no known medical diagnoses. Her only medication was ½ of a multivitamin daily. In the months before her admission she appeared to be failing. She was eating less, had lost 30 pounds in a three month period and had lost her ability to walk independently due to her generalized weakness. However, she remained continent and oriented. She was hospitalized in OCT 2012 to be evaluated for this decline and weight loss and no cause was identified. She received IV hydration to correct the mild dehydration that had developed as a result of her inadequate oral intake. She was sent home on hospice and continued to decline and died comfortably at home about 6 weeks after admission. As a physician, I considered her advanced age, lack of discernible cause for decline, loss of ability to independently ambulate, significantly reduced oral intake, 30 pound weight loss in three months, and rating of 40% on the Palliative Performance Scale (PPS) as prognostic indicators for a life expectancy. While all of these were factors in her decline, there was no identified diagnosis that was cause for her decline and death, so she was coded by our hospice as “Failure to Thrive.” In my experience as a hospice physician, I see many patients at this point in their lives who refuse hospitalizations and do not want any interventions to reverse the decline. They are “done” but still very much eligible for hospice. Our hospice supported her natural dying process by keeping her comfortable, provided counseling services to the patient and their family about signs and symptoms of impending death, and allowed the patient to stay at home, where she wanted to be for the remainder of her life. I think she is a good example of the small but very real number of patients who are and should be coded as “Failure to Thrive” or debility unspecified. To code them otherwise would involve assigning diagnoses they do not have or would not result in their death.

Assigning a code that is not supported would be contrary to ICD-9-CM Guidelines for Coding and Reporting. Relative to “uncertain diagnosis,” the Guidelines state “Do not code diagnoses documented as ‘probable,’ ‘suspected,’ ‘questionable,’ ‘rule out,’ or ‘working diagnosis’ or similar terms indicating uncertainty. Rather, code the condition(s) to the highest degree of certainty for that encounter/visit, such as symptoms, signs, abnormal test results, or other reason for the visit.”

**Private sector use of debility and adult failure to thrive**

The proposed rule states that CMS believes that the private sector will not allow “debility” and “adult failure to thrive” as principal diagnoses on private sector hospice claims. In discussing this issue with many hospice physicians, they could never recall

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receiving a denial from a private insurance carrier based solely on the use of either of these as the primary diagnoses on a claim.

Return to Provider (RTP) Directive

From the proposed rule: When reported as a principal diagnosis, ["debility" and “adult failure to thrive"] would be considered questionable encounters for hospice care, and the claim would be returned to the provider for a more definitive principal diagnosis. “Debility” and “adult failure to thrive” could be listed on the hospice claim as other, additional, or coexisting diagnoses. We believe that the private sector requires that ICD–9–CM coding guidelines be followed; this includes not allowing “debility” and “adult failure to thrive” as principal diagnoses on private sector hospice claims.

NHPCO understands that a Change Request (CR) will be issued to provide direction to the MACs on the requirement to Return to Provider (RTP) claims when either the “debility” or “adult failure to thrive” diagnoses are used. We respectfully request that this directive be reconsidered. As illustrated by the previous clinical examples, there are hospice patients for whom “debility” or “adult failure to thrive” remains the best diagnosis describing the patient’s terminal condition. In these cases, it seems more cost effective to ask the provider to submit additional supporting documentation with the claim when these diagnoses are used, rather than to incur the expense of returning the claim to the provider and delaying payment. If, however, the decision is made to return these claims, we ask that the directive set an RTP date far enough into the future to give providers the opportunity to complete the review of their current patients with these two diagnoses in order to try and identify alternative primary diagnoses.

3. Use of “Mental, Behavioral and Neurodevelopmental Disorders” ICD–9–CM Codes

From the proposed rule: Another concerning trend noted in the top twenty claims-reported principal hospice diagnoses is the use of codes that fall under the classification of “Mental, Behavioral and Neurodevelopmental Disorders.” There are several codes that fall under this classification that encompass multiple dementia diagnoses that are frequently reported principal hospice diagnoses on hospice claims, but are not appropriate principal diagnoses per ICD–9–CM Coding Guidelines. Some of these ICD–9–CM codes are considered manifestation codes. In accordance with the 2012 ICD–9–CM Coding Guidelines, certain conditions have both an underlying etiology and multiple body system manifestations due to the underlying etiology. For such conditions, the ICD–9–CM has a coding convention that requires the underlying condition be sequenced first followed by the manifestation.
NHPCO believes that many patients with Alzheimer’s or other dementias were mistakenly coded in the Mental, Behavioral and Neurodevelopmental Disorders classification. Perhaps a better coded diagnosis would be 294.2 – Dementia, unspecified (+ 5th digit modifiers).

In fact, the 2012 ICD-9-CM code book published by OptumInsight (f/k/a Ingenix) provides the following “Coding Tips” for unspecified dementia:

New code 294.21 reports unspecified dementia with behavioral disturbances, which includes aggression, combativeness, violence, and wandering. New subcategory 294.2 provides a means by which to classify unspecified dementia, allowing those conditions to be separately reported, if necessary. This code is reported when the underlying cause has not been definitively established.4

With additional education on coding conventions, the use of this classification of codes by hospice providers can be minimized and the Alzheimer’s disease and other dementias diagnoses can be appropriately classified under the “Diseases of the Nervous System and Sense Organs” with manifestations/etiology coded appropriately. Again, there may be rare instances in which these are the best codes to describe a given patient's condition and we respectfully request that their use be discouraged but not prohibited. NHPCO will be pleased to collaborate with CMS, other hospice associations and coding experts to offer hospice provider education on the appropriate use of codes for patients with dementia to ensure clearer understanding of the coding schema.

4. Guidance on Coding of Principal and Other, Additional, and/or Co-existing Diagnoses

Use of UHDDS

From the proposed rule: Based on the ICD–9–CM coding guidelines, the circumstances of an inpatient admission always govern the selection of principal diagnosis. The principal diagnosis is defined in the Uniform Hospital Discharge Data Set (UHDDS) as “that condition established after study to be chiefly responsible for occasioning the admission of the patient to the hospital for care.”

We believe that the language in the proposed rule directing hospice providers to comply with the UHDDS is inappropriate, and is, in fact, not required according to another

section of the ICD-9-CM Coding Manual. In the ICD-9-CM Coding Manual, Section IV, Diagnostic Coding and Reporting Guidelines for Outpatient Services section, it states:

The Uniform Hospital Discharge Data Set (UHDDS) definition of principal diagnosis applies only to inpatients in acute, short-term, long-term care and psychiatric hospitals.\(^5\)

The diagnosis responsible for the patient’s most recent hospitalization is not necessarily the diagnosis establishing their hospice eligibility. In many cases, the hospice admission team will have no knowledge of the patient’s last inpatient admission and the admitting diagnosis, and should not be dependent on that information to determine eligibility and hospice admission. The determination of the patient’s admitting hospice diagnosis is based on the initial and comprehensive assessment completed by the hospice interdisciplinary team, the review by the hospice medical director or hospice physician, and the selection of a hospice diagnosis. As noted in the example below, the hospital admitting diagnosis may be quite different from the principal diagnosis supporting hospice eligibility.

**Case Example:** Elderly nursing home resident presents from the LTCF to the hospital emergency department with acute respiratory distress. Evaluation reveals pneumonia, resulting in hospitalization. During the time in the hospital, it is determined that the pneumonia is actually due to aspiration. She is noted in the hospital to have significant cognitive changes, which are described as acute delirium. She is referred to hospice upon hospital discharge, with a hospital discharge diagnosis of Aspiration Pneumonia (507.) and Acute Delirium due to her infections (293.0). The hospice physician, in evaluating the patient for certification, determines that the patient has underlying Alzheimer’s Disease (331.0), which is the actual underlying cause of her aspiration pneumonia and is the more appropriate diagnosis for hospice admission. The hospital and hospice diagnoses should be different.

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B. Proposed Update to the Hospice Quality Reporting Program

1. Quality Measures for Hospice Quality Reporting Program and Data Submission Requirements for FY2015 and Beyond

From the proposed rule: We solicit comment on the removal of the checklist and data source questions from the structural measure, and the removal of the NQF #0209 measure. We also solicit comment on the alternative proposal of maintaining NQF #0209 until another pain outcome measure is available.

Under law, as part of the new Medicare Hospice Quality Measurement Program, hospice programs are required to publicly report quality data to the federal government or incur a financial penalty beginning in FY 2014. CMS required that hospices report two quality measures for payment determination for FY 2014 and FY 2015 (i.e., NQF #0209, an outcome measure focused on pain management and a structural measure indicating whether the hospice has a Quality Assessment and Performance Improvement program that includes at least three quality measures related to patient care.)

CMS has proposed that the structural measure related to QAPI indicators and the NQF #0209 pain measure would not be required for the hospice quality reporting program beyond data submission for the FY 2015 payment determination. The primary stated purpose of the structural measure was gathering data to ascertain the breadth and context of hospices’ QAPI programs. CMS has determined that adequate information has been collected from this measure and, therefore, NHPCO supports the discontinuation of the measure. In announcing the discontinuation of the QAPI structural measure, CMS should make it clear in its communication to hospice providers that only the QAPI structural measure is being eliminated and that the requirements for QAPI programs remain in place as delineated in the Hospice Conditions of Participation.

NHPCO does not, however, support the elimination of NQF #0209 from the hospice quality reporting program beyond the FY 2015 payment determination. Pain is highly prevalent during the final phase of life, so the timely evaluation and treatment of pain at the time of admission, before the patient is either unable to respond or detailed assessment becomes an additional burden, is a priority. As an outcome measure that evaluates hospices’ effectiveness at managing pain at the start of service, NQF #0209 addresses a fundamental aspect of hospice practice and reflects patient-centered care. This measure is particularly significant to hospice because it ensures integration of patient choice for desired level of treatment with the care process by incorporating the patient’s own pain goals and perception of his or her own degree of comfort. As stated
in the CMS User Guide for Hospice Quality Reporting Data Collection: “Because the measure incorporates both patient preference and measure outcomes, it is useful and meaningful for consumers, providers, and payers.”

CMS states that in making the decision to discontinue the use of NQF #0209, findings from the Voluntary Reporting period and the Hospice Item Set pilot were considered, but data from the first year of reporting were not yet examined. The Voluntary Reporting data submission included only structural measure data. And, while some hospices that had implemented NQF #0209 prior to the required data collection period (4th quarter of 2012) may have included NQF #0209 in their Voluntary Reporting submission, this submission was certainly not sufficiently relevant in content or volume to inform decision making related to NQF #0209. Therefore, the decision to discontinue NQF #0209 has been made primarily based on data from the HIS pilot which was collected from just 9 hospices over only a few months.

In discussing the implementation of the HIS, CMS states that “typically the first two quarters of data reflect the learning curve of the providers as they adopt a standardized data collection.” This same learning curve was undoubtedly also experienced by hospices for at least the first quarter of implementation of NQF #0209. The initiation of quality reporting in 2012 - and the concomitant implementation of a predetermined measure with specifications that cannot be modified – was a new and understandably challenging experience for the hospice community. Hospices have been required to systematically employ performance measures in their QAPI programs for a relatively short period of time. Most hospices have developed their own quality indicators and performance measures for these programs. Many of the hospices that have incorporated predetermined measures, such as NQF #0209 or PEACE measures, into their QAPI programs have made modifications to the measures – an appropriate practice for quality improvement purposes.

Until the advent of quality reporting hospices were accustomed to utilizing their own measures or modifying existing measures in their QAPI programs. The advent of hospice quality reporting meant for the first time all hospices were required to implement a measure – NQF #0209 - according to specifications and adherence to a protocol that they could not modify.

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CMS has stated concern that NQF #0209 “does not easily correspond with the clinical processes for pain management resulting in variance in what hospices collect, aggregate, and report.” It is true that for some hospices, implementation of NQF #0209 has proven to be a challenge. However, the difficulty hospices may have experienced is not because the measure is inherently at odds with pain management practice. In fact, the measure was developed by clinicians and designed intentionally to reflect what should be an outcome of good pain management – i.e., that pain management is based on patient goals and is accomplished in a timely manner.

The variation that is of concern to CMS is not the result of a misfit between the measure and hospice practice. Instead the observed variation is a natural result of the first instance of all hospices in the country being required to conform to measure specifications and adhere to a protocol for measure implementation that could not be altered. Even some of the hospices that were using NQF #0209 prior to the initiation of quality reporting found it challenging to conform to the requirements because they had modified the measure and had to reeducate staff and retool documentation to comply with the original specifications. Over the past year, hospices have applied focused effort and resources to implement the NQF #0209 measure, train staff, and develop data retrieval capabilities -- and just now are able to see the results of these efforts.

CMS states that it in deciding to consider elimination of NQF #0209 from quality reporting, provider comments and questions submitted to the hospice quality help desk during the 2012/2013 data collection and reporting period were considered. NHPCO cautions against over reliance on help desk inquiries as an indication of the suitability or utility of NQF #0209 for inclusion in the HQRP. We remind CMS that a substantial volume of questions coming into a help desk when a new measure is introduced is to be expected. This was not only the case for the hospice community, but was compounded by the simultaneous initiation of quality reporting for the first time. Despite this, many hospices were able to implement the measure and not only met the reporting requirements, but experienced additional unanticipated benefits (e.g., revision of staff competencies on pain management; better pain outcomes over the entire course of service). These hospices did not call the help desk; CMS heard from only those hospice providers who needed assistance.

CMS has also expressed concern about the validity of NQF #0209 because of the large number of ineligible patients, but provided no results in the proposed rule to support this statement. In contrast, no concerns were raised related to the validity of the
measure during the National Quality Forum endorsement process in 2011. CMS should examine at least a full year of data before questioning the validity of the measure.

Regardless of the legitimacy of this concern, patient report is unquestionably the best data source for symptom-related and other outcome measures for the hospice patient population. Outcome measures, such as mortality and morbidity which are used by other healthcare providers and settings, have no utility for hospice. Because many hospice patients are cognitively and physically impaired due to advanced illness, the number of patients who are able to self-report is limited. However, because symptom management is such an essential aspect of hospice practice, this fact should not preclude inclusion of outcome measures based on self-report for hospice quality reporting. This is particularly true for outcome measures related to pain management.

Pain management is central to the provision of hospice care. If NQF #0209 is eliminated, the HRQP will include only two process measures related to pain management (NQF #1634 Pain Screening and NQF #1637 Pain Assessment). Even though these measures received endorsement by the National Quality Forum, the NQF submission for these measures did not include evidence that they are associated with positive patient outcomes. It is also highly likely that these measures will quickly demonstrate a ceiling effect, and consequently, may not be retained after the planned analysis that will determine which measures are selected for public reporting. Even if these two measures do demonstrate the ability to distinguish among hospices on the quality of services provided, the meaning for the public of pain screening and pain assessment is questionable. Screening for and then assessing pain are only the first steps in pain management, and the relative importance of those steps to successful pain management is not readily obvious to non-clinicians. However, the public can relate to whether a hospice can achieve comfort for its patients – which is what NQF #0209 demonstrates.

Outcome measures are recognized as the best and most desirable means by which to evaluate quality. One of the policy recommendations from the authors of a recent report sponsored by the Robert Wood Johnson Foundation and the Urban Institute, titled Achieving the Potential of Health Care Performance Measures, is to “decisively move from measuring processes to outcomes.”7 Recent testimony by several experts

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before the Senate Finance Committee on the state of quality improvement in healthcare forcefully called for fewer process measures and a stronger focus on outcomes of care rather than on how care is delivered. The Measure Applications Partnership (MAP) has also consistently identified the need for more outcome measures across all healthcare providers. NQF #0209 was among the measures for the HQRP that CMS submitted to the MAP in 2012 in advance of 2013 rulemaking. In so doing, CMS gave no indication to the MAP that NQF #0209 would be proposed for elimination after its use for 2015 APU determination. Given that the MAP not only recommended that NQF #0209 continue to be part of the HQRP but included the measure for consideration for implementation by other providers as well (i.e., the Physician Quality Reporting System (PQRS) program), it is doubtful that the MAP would have reacted favorably to its proposed removal from the HQRP.

CMS states its intention to “work toward the HQRP’s future inclusion of an improved pain outcome measure” and has proposed that NQF #0209 be maintained until another pain measure is available as an alternative to removing NQF #0209 from the HQRP. As an outcome measure that evaluates hospices’ effectiveness at managing pain at the start of service, NQF #0209 addresses a fundamental aspect of hospice practice and reflects patient-centered care. NHPCO believes that CMS’ elimination of quality reporting for NQF #0209 after only one quarter of data collection and submission is exceedingly premature and we strongly recommend that CMS maintain NQF #0209 at least until another pain outcome measure is available and possibly longer. There has not been sufficient evaluation of the data nor has there been adequate consideration of the myriad of factors operating in the initial implementation of quality reporting for hospice to conclude that NQF #0209 “is not suitable for long term use” in the HRQP.

In addition, NHPCO requests that CMS conduct an examination of the NQF #0209 2013 data submission and then compare the results to the HIS data when available. We believe that the comparative findings will show that NQF #0209 will have performed at least as well as the measures included in the HIS. Furthermore, NHPCO recommends that CMS in the meantime continues to support hospices in implementation of NQF #0209 through provision of education and other resources to ensure reliable generation, documentation, and reporting of measure data. NHPCO unreservedly offers to collaborate with and assist CMS in these endeavors.
Given the recognized value of outcome measures and their accepted superiority over process measures in evaluating healthcare quality, it was both fortuitous and advantageous that a NQF endorsed outcome measure (NQF #0209) related to pain management was available for inclusion in the initial year of the HQRP. It would be detrimental to the quality reporting program and the hospice community to substitute pain management process measures for an outcome measure after only a little over a year of usage. To quote the authors of the aforementioned RWJF/Urban League report, “The operational challenges of moving to producing accurate and reliable outcome measures are daunting but worth the commitment.”

NHPCO asks that CMS heed this advice.

2. Quality Measures for Hospice Quality Reporting Program for Payment Year FY2016 and Beyond

From the proposed rule: We contracted with RTI International to support the development of the Hospice Item Set (HIS) for use as part of the HQRP. In developing the HIS, RTI focused on the NQF endorsed measures that had evidence of use and/or testing with hospice providers.

We have included data items that support the following NQF endorsed measures for hospice:

- NQF #1617 Patients treated with an opioid who are given a bowel regimen
- NQF #1634 Pain screening
- NQF #1637 Pain assessment
- NQF #1638 Dyspnea treatment
- NQF #1639 Dyspnea screening
- NQF #1641 Treatment preferences
- NQF #1647 Beliefs/Values addressed (if desired by the patient)

CMS proposes an expansion of the required HQRP measures to include additional measures endorsed by NQF and has developed a hospice patient-level data collection instrument (HIS) to support the standardized collection of the data elements needed to inform those measures. NHPCO understands and concurs with the idea that

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standardization of data collection is important for the hospice community in order to have meaningful data for future quality reporting.

CMS states that most of the measures endorsed by NQF are already widely in use by hospices nationwide as part of their internal Quality Reporting and Performance Improvement (QAPI) programs. However, NHPCO cautions CMS not to underestimate the significant challenges hospices will face in the simultaneous implementation of seven performance measures and the data collection tool to gather data for those measures.

Data collection is only one element in measure implementation. Implementation of new measures at the same time as a data collection tool presents a significant challenge if the proposed data submission start date of July 1, 2014 is put in place. Consideration needs to be given to the impact on hospices of the concurrent implementation of a data collection tool and new measures.

While it is true than many hospices have incorporated some PEACE measure into their QAPI programs, the initiation of the HIS will require implementation of seven new measures at the same time for a multitude of hospices. Additionally, the measure specifications and other information available from NQF for most of the endorsed measures are not sufficiently detailed to provide the full complement of information necessary for implementation. Consequently, hospices have had to “fill in the gaps” by developing their own protocols for measure implementation. In many cases, these hospices will need to reeducate staff, and retool documentation and data retrieval systems in order to generate, document, and retrieve data that conforms to the HIS requirements.

There is a multitude of vendors who supply software to those hospices that utilize electronic patient records and the addition of seven measures will pose a challenge to these vendors that will translate into an additional burden for hospices as well. The necessary software upgrades will involve development of new programming and extensive testing – a process that requires a significant amount of time. It is uncertain whether the software vendors will have the needed capability for data collection in place in time to begin data submission by the July 1 start date proposed by CMS. The software upgrades will need to be in the hands of the hospices well before July 1 to give them time to educate staff on documentation and learn how to extract the data, plus perform adequate testing of their systems to ensure accurate operation. It is very possible that hospices will have to institute a paper system for at least part of the data
process until the software is functioning at a level that reliable data generation, documentation, and retrieval can be assured.

The calculation by CMS of the time required to complete the HIS Admission and Discharge forms (19 minutes and 10 minutes respectively) may be an underestimation. This will certainly be true during the initial implementation of the HIS, but may also be the case long term. The structure of the patient record and the processes for data retrieval are dictated by the software utilized and will greatly influence the amount of time required to complete the HIS forms. Because hospices have limited ability to modify the structure and processes of their electronic patient records, even with maximum efforts devoted to achieve efficiency, data retrieval may exceed the CMS time estimates by substantial amounts.

In addition, thoughtful consideration should be given to the burden of data collection on the family, particularly when the patient is admitted to hospice services in the last days of life. According to NHPCO data, in 2011, over thirty-five percent of hospice patients had a length of service of seven days or less. Interaction with patients and families at this critical time must be focused on what is important to the patient/family caregiver and meeting their needs. CMS should consider exempting hospices from using the standardized data collection tool or allowing truncated data collection when circumstances warrant (e.g., patient is actively dying; patient/family in crisis).

CMS states that it will provide hospices with further information and details about the use of the HIS. The existing materials submitted to the OMB under the Paperwork Reduction Act (HIS Admission and Discharge forms plus accompanying Item Descriptions documents for each) are not sufficiently comprehensive and detailed and, consequently, will not facilitate the standardized collection of the data elements that is the stated goal of the HIS. Much more detail will be needed in order for these measures to be implemented consistently across hospices – and consistency in implementation is critical to having reliable data.

NHPCO urges CMS to develop highly detailed, in-depth support materials (e.g., data collection user guidelines; data dictionary, etc.) related to data generation and documentation for each of the data elements in the HIS forms. Additionally, hospices need to be informed how each data element relates to the specifications and scoring for each measure, as well as how all of the collected data, including the administrative data, will be used.
The HIS forms and the Item Descriptions are not self-explanatory and leave a great deal open to interpretation. The following are examples of issues related to the data elements on the HIS forms where clarification is needed to ensure consistent data collection across hospices. This is only a partial list and is far from inclusive of all areas that require additional explanation and amplification.

- **Timeframe for the generation of the data elements.** It appears that the HIS Admission form is designed for data generation and documentation to occur on the initial nursing and comprehensive assessments, but it is not clear if that is the expectation.

- **Responsibility for generation and documentation of data.** While it is logical to expect that data related to pain, dyspnea, and bowel regimen for patients on opioids will be generated by the nurse during the initial nursing assessment, data related to life-sustaining treatment preferences, hospitalization preference, spiritual concerns may be generated by other hospice team members during the comprehensive assessment. Guidance is needed regarding which team members may or are expected to generate and document each data element.

- **Meaning of the Admitted From data element (A1802).** It is difficult to ascertain the relevance of this data element in the context of hospice. For example, a patient may have been a resident in a skilled nursing facility for many years when admitted to hospice care. The patient will remain in the facility and hospice will provide services for this resident there. Presumably, the response to both the Site of Service at Admission (A0205) and Admitted From (A1802) data elements would be the same (04 Skilled Nursing Facility), but the reasoning behind asking both of these questions is not clear.

- **Definition of spiritual/existential concerns (F3000).** Clarification is needed regarding what constitutes spiritual/existential concerns and whether it is the spiritual concerns of the patient’s, the caregiver’s, either or both that are expected to be addressed. Also, in some situations asking about spiritual concerns may not be appropriate. For example, if the patient does not have the cognitive ability to be questioned about spiritual concerns and there is no family caregiver (e.g., an attorney is the decision maker for the patient) asking about spiritual concerns would not appropriate, yet no accommodation is made for this in the data collection.
Of particular concern are the items for Pain Screening in Section J of the Admission form (J0900). CMS has chosen to define pain screening to include both ascertaining the presence of pain and assessing the severity of the pain. While it is appropriate to include a pain severity/intensity rating as part of a pain screening, the HIS form incorrectly labels the list of pain intensity assessment tools and methods as pain screening tools. These tools may be utilized in the screening process but are not screening tools – they are tools for assessing pain severity/intensity. This mislabeling may cause confusion and mislead clinicians. NHPCO recommends that CMS provides an explanation that pain intensity assessment part of the pain screening process for the HIS and that the tools listed are utilized for assessment of pain severity.

Of even greater concern is the data element that asks for the patient’s pain severity. There is no established accepted correlation between the categories of pain intensity listed on the HIS form and the pain intensity ratings yielded by the multitude of pain intensity scales that are available for use in the hospice population. Consequently, a clinician entering data on the form for this data element will essentially be guessing at the response. Consistent data collection for this data element is not possible and, therefore, it has no utility for evaluating quality of service delivery among hospices. NHPCO strongly recommends that this data element be deleted from the HIS. Even if the intended use of the data from this element is for descriptive purposes and not evaluation of quality, the presence of the data element on the form implies that clinician opinion of pain severity is acceptable data – which it is not.

3. Public Availability of Data Submitted

From the proposed rule: The Affordable Care Act requires that reporting be made public on a CMS Web site and that providers have an opportunity to review their data prior to public reporting. CMS will develop the infrastructure for public reporting, and provide hospices an opportunity to review their data. In light of all the steps required prior to data being publicly reported, we anticipate that public reporting will not be implemented in FY 2016. Public reporting may occur during the FY 2018 Annual Payment Update (APU) year, allowing ample time for data analysis, review of measures’ appropriateness for use for public reporting, and allowing hospices the required time to review their own data prior to public reporting.

NHPCO is pleased that CMS plans to establish the reliability and validity of the process measures supported by the HIS data collection prior to public reporting and that
hospices will have the opportunity to review the data regarding the hospice’s respective program before it is made public.

Providing results of process measures in a way that is meaningful to the public will be a particular challenge in the context of hospice care, given the general lack of knowledge on the part of the public of the various components of hospice care let alone what constitutes quality in hospice. NHPCO shares CMS’ conviction that it is essential that data made available to the public be meaningful. To that end, NHPCO requests that CMS give consideration to the difficulty that the public will likely have understanding the relationship of process measures to quality of care, and that a comprehensive explanation of this relationship be provided for the process measures that are publically reported.

Because results from the proposed Hospice Experience of Care Survey reflect the experience of family caregivers of hospice patients, it is possible that quality measures derived from the survey will have more meaning to the public than results from process measures. Therefore, NHPCO recommends that CMS include in public reporting measures developed from the Hospice Experience of Care Survey when available.

Similarly, as stated earlier, results from NQF #0209 are also likely to be understood and have meaning for the public – anyone should be able to relate to whether patients in pain were able to achieve comfort within 48 hours after the start of hospice care. If NQF #0209 is retained, NPHCO requests that it be included in public reporting.

Also, if NQF #0209 is publicly reported, CMS should consider approaches to reporting the results as an alternative or adjunct to the score calculated according the measure specifications. Two such alternate approaches would be to create an adjusted score calculated after removing the patients from the denominator who were unable to self-report at follow-up; or to create a problem score by dividing the number of patients who responded “no” their pain was not brought to a comfortable level by the original value for the denominator. Many hospices have voiced concern that the NQF #0209 scoring methodology created a distorted picture of their performance. By utilizing data from only those patients who are able to respond at follow-up, both of these approaches for adjusting scores provide a more focused picture of a hospice’s ability to provide effective and timely pain management immediately after start of care. NHPCPO would be pleased to collaborate with CMS on developing alternate approaches to reporting NQF #0209 results.
4. Proposed Adoption of CMS Hospice Experience of Care Survey for the FY2017 Payment Year

From proposed rule: The Hospice Experience of Care Survey captures such topics as hospice provider communications with patients and family members, hospice provider care, and patient and family member characteristics. The survey would allow the informal caregiver (family member or friend) to provide an overall rating of the hospice care their patient received, and would ask if they would recommend “this hospice” to others.

NHPCO supports the use of an experience of care survey as a data source for quality measures in addition to patient record based quality measures. A post-death survey completed by family caregivers is particularly useful for evaluating the entire episode of hospice care and is uniquely suited to the hospice approach that envisions the patient and family as the unit of care.

Many hospices currently utilize the Family Evaluation of Hospice Care (FEHC) survey as the cornerstone of their QAPI programs. These hospices are already familiar with evaluation of quality of care based on responses from family caregivers to a post-death survey. However, the transition to a new survey will not be without its challenges. FEHC users will need to thoughtfully plan how navigate the transition to a new survey and the results from new measures based on that survey and still maintain a viable and robust QAPI program.

Another challenge will be the very short time between the start of data submission using the HIS (July 1, 2014) and the start of administration of the Hospice Experience of Care Survey (Jan – March, 2015). Hospices will need to contract with an approved vendor for survey administration and will need time to make an informed choice. Also, those hospices that do not currently use a vendor for FEHC administration will need to develop a system to extract the relevant patient and caregiver information that will need to be conveyed to the vendor. Even those hospices that have such a system in place will need to modify it to include the site of death so that the appropriate survey will be mailed.

However, the greatest and most significant challenge facing hospices is the substantial additional resources required by the expansion of the HQRP. Both HIS and CAHPS implementation will necessitate significant expenditures in terms of money and staff time. Preparation for the processes involved in the implementation of new measures and a data collection tool plus a new survey will create a sizable burden for hospice
providers and a strain on resources during a period of ongoing reductions in payment. Even though these measures reflect basic hospice practice, considerable time, manpower, and financial resources are required to ensure consistent data generation, documentation, and retrieval from patient records of any new measure. This expenditure is magnified with the number of new measures to be implemented at the same time.

The rapid implementation of additional measures and data collection means that expenditures will occur over a short period of time – and coincides with multiple other new requirements (adjustments in coding practices, transition to ICD-10 coding, additional patient data collection, changes to the Cost Report requirements). The impact of these additional demands comes at the same time as the current reductions in hospice payment (BNAF, sequestration, productivity factor) and the coming payment reform may further reduce payments to hospice. This combination of increased requirements and reduced revenue may be more than some hospices can sustain but might be avoided if hospices had more time to implement the new requirements.

NHPCO requests that CMS give serious consideration to modifying the proposed schedule for expansion of the HQRP. NHPCO stands ready to work with CMS on securing a delay to the January, 2016 implementation of the value-based purchasing demonstration for hospice. A delay would mean that HQRP can expand at a slower pace which would maximize the reliability of quality measure data collection and will benefit both hospice providers and CMS.

D. Update on Hospice Payment Reform and Data Collection

Even though no proposals are being put forth at this time, NHPCO appreciates CMS providing information regarding its ongoing hospice payment reform efforts and some of the options being considered. As we have indicated in the past, we continue to feel compelled to express the hospice community’s concerns that the notion of payment reform has been based largely on apprehensions about growth in the utilization of hospice care, and particularly with increases in the number of hospice patients with long lengths of stay in hospice. Rather than simply address specific concerns, the response has been to consider fundamental changes to a benefit that has served Medicare beneficiaries well for over 30 years, and that not only saves Medicare money,9,10 but provides care through the type of integrated and interdisciplinary model that CMS is trying to move much of the health care system towards.

In recent years, a number of changes have already been made, with hospice community support, to address concerns with long stay patients, and ensure the more active engagement of hospice physicians. Efforts are on-going, as evidenced in this proposed rule, to collect and analyze more detailed and comprehensive data about the patients served by hospice, the services provided by hospices, and the cost of providing that care. However, we want to urge CMS to focus its payment reform efforts on addressing problems that can be clearly identified and defined, and not to undertake significant re-structuring of a Medicare benefit that enjoys unparalleled levels of beneficiary satisfaction, is demonstrably cost effective, and is already threatened by the need to absorb several significant and ongoing cuts in payment, increased (and continuing) costs to comply with additional regulatory requirements, and an additional two percent reimbursement cut through sequestration.

As noted below in more detail, while CMS’s efforts to collect more, and more accurate, data about hospice patients and hospice services are underway, these efforts are incomplete and are, at this point, of limited value. Much of the data comes from the hospice cost reports, which have never been audited and which CMS has acknowledged are flawed. NHPCO will be commenting separately on the draft cost report forms and instructions recently released by CMS for review. We urge CMS not to move forward with payment reform proposals until more, and more accurate, data is available. And to do so only after a careful analysis of the effects of any reform proposal both on hospices’ ability to continue to provide the comprehensive and high quality care that beneficiaries deserve and expect, and on beneficiaries’ access to hospice care in all areas of the United States and in all settings. Equally important, when CMS does devise a new payment methodology for the hospice community, it needs to be tested with a small but representative group of hospice providers, in a variety of settings over a reasonable and definite period of time to ascertain its impact on the high quality of care provided by the nation's hospice programs, and guarantee patients and families access to compassionate end of life care.

We are particularly concerned with CMS and MedPAC’s focus on hospice provided to some of the frailest and most vulnerable Medicare beneficiaries; those who reside in nursing homes. As addressed in more detail below, we urge CMS to tailor any changes to the way hospice care is reimbursed and provided to nursing home residents to address specific and well documented problems, and not to apply across the board payment reductions in this site of service based on incomplete analyses of the complex end of life care being delivered to residents of nursing homes, or to undertake such changes based on assumptions and conjectures about this patient

population, the care they receive, and how it is provided. Indeed, as problems are identified in this area, regulatory or administration reforms ought to be the first path to address the particular issues, with a focus on a "surgical" approach to the issue, and not through the use of across the board reimbursement changes that affect all providers.

1. **Update on Reform Options**

Again, we appreciate the information about CMS’s research and efforts towards developing and analyzing different payment models. We urge CMS to be careful and deliberate in any restructuring of the hospice reimbursement model, and to ensure that before proposing changes it not only has the necessary data for analyzing any reform models, but that the data is accurate and comprehensive, and represents the broad range of hospice providers, including small and rural providers. Over seventy five percent of the hospices in the United States have fewer than 500 admissions per year, and CMS must be mindful of the effects of any payment reform on small hospices for whom increased administrative and regulatory requirements are a particular challenge. We also would caution CMS to ensure that any efforts to address current concerns about small numbers of long stay patients does not end up incentivizing the admission of short stay patients, where the care provided is often “crisis care” and does not allow the patient and their family to experience the full range of hospice services. The high percentage of patients admitted to hospice with extremely short stays has been a persistent and troubling problem for hospices, and deprives patients of the full benefit that hospice care can provide.

We note, in particular, that CMS has indicated it will consider whether case mix adjustment should play a role in determining payment, which provides an opportunity to illustrate one of our concerns. In discussions with hospice clinicians throughout the country, there have been strong reactions to the idea that “more diagnoses” makes for more complex care. In fact, the number of diagnoses listed on the claim form for a patient does not correlate with the acuity of the patient and the needs of the family, nor does it accurately predict the trajectory of the patient’s condition. When considering any kind of case mix adjustment, we urge CMS to look at other factors, ensuring that patient acuity is at the forefront.

**Rebasing the Routine Home Care (RHC) Rate**

While we understand that CMS is not proposing to rebase the RHC rate at this time, we’re extremely concerned that CMS is even considering the possibility, and has calculated a possible new rate that would represent an 11.4% reduction in the rate that is paid for 97% of patient care days. CMS acknowledges that it doesn’t have the data to support rebasing six of the nine cost components used to calculate the original RHC rate. Furthermore, the data that is available comes from the hospice cost reports, which were neither designed for, nor have ever
been used for, payment purposes, and they have never been audited, so we question the accuracy and completeness of the data.

Despite a history of attempts to ensure uniformity, we know that hospices’ completion of the cost reports is inconsistent and that their interpretation of certain data elements varies from provider to provider. Provider-based hospices, for example, have far less detailed information on the cost of hospice care when compared to free-standing hospice cost reports. For example, as CMS’s own contractor, Abt Associates, found in its review of cost reports regarding hospice inpatient care, a significant number of cost reports indicated that the hospice had zero costs for inpatient care but also reported that they did provide days of inpatient care. Much of the challenge with data accuracy is the result of confusion among hospice providers about exactly where certain data elements should be placed when completing the cost report and lack of clarity in the instructions.

NHPCO submitted recommendations in June 2009 to address many of these areas of confusion and will be commenting on the draft forms and instructions in a separate comment letter. While NHPCO will be addressing draft changes in the cost report in separate comments, we have significant concerns with the newly released draft cost report and the ability of hospice providers to separate their costs appropriately so that CMS will have usable data for analysis. CMS should consider early in the process what kind of review and analysis can be undertaken to identify problem areas in cost report completion, and make adjustments in instructions and in CMS-offered training. NHPCO stands ready to work collaboratively with CMS to address concerns in the draft cost report forms and instructions, and to offer cost report training once the new cost report forms and instructions are final.

And while we would object to any efforts to simply “inflate” the 1983 costs per day for the six cost components for which CMS has no current data, this is particularly inappropriate to the extent it would use the same inflation factor for drugs, supplies, equipment and the other components when the costs of each category have risen by different percentages over the past thirty years. We note that the “average” cost was used as an inflation adjuster for several of these categories, when a much more predictive statistic is to use the median. For instance, in the NHPCO analysis of the FY2011 hospice cost report, the median cost of drugs for FY2011 is $8.27, significantly different than the “average” of $3.74 as stated in the proposed rule.

We would also note that the nine cost components used in 1983 don’t include at least one of the disciplines involved in providing hospice care (chaplains). In addition, the role of the hospice physician has significantly increased since the issuance of the final rule in 1983, and the 9 original cost components do not take that increased responsibility into account. Many of the
hospice physician responsibilities are covered under the Routine Home Care rate and are not billed to Medicare separately. Any effort to rebase the rates should look anew at the requirements in the routine home care rate, take into account changes from the 2008 Medicare hospice conditions of participation and whether these components of care apply in 2013.

Beyond any efforts to thoroughly analyze and understand the implications of existing data, any notion of rebasing is misplaced and totally out of context, given the challenges that are facing the ever growing hospice patient population and the atmosphere of continued budget pressures being translated into further reimbursement cuts for the hospice community. In addition, rebasing does not take into account the small margins hospice providers have consistently had each year, as reported by MedPAC. While rebasing is an unlikely path to positive improvement for Medicare beneficiaries, the value-add of such an undertaking pales in comparison to other more important and timely exercises for CMS.

**Site of Service Adjustment for Hospice Patients in Nursing Facilities**

NHPCO is particularly distressed by CMS’s indication that it is considering a “site of service adjustment” that could possibly result in lower payment rates for hospice care provided to residents of nursing facilities. We believe that the assumptions underlying such a payment reduction lack supporting data and are based on incomplete information regarding how hospice care is delivered and paid for in the nursing home setting, and on the needs of the hospice patients who reside there. NHPCO strongly disagrees with the suggestion that hospices enjoy “efficiencies” when they care for terminally ill nursing home residents that would justify a payment reduction, or that hospices are providing too many services to this most vulnerable subset of the Medicare population. Wholly missing in any of the aforementioned discussions of the so-called "efficiencies" are the demonstrable "inefficiencies" of delivering this essential and compassionate care to patients and families who find themselves, for a variety of reasons, in nursing home facilities.

The Medicare hospice benefit was created over 30 years ago to provide comprehensive and compassionate care to terminally ill beneficiaries, and to give individuals the kind of end-of-life care they wanted, in the setting they call home. That home may be a long-time residence in the community, a son or daughter's home, an assisted living facility, or a nursing facility. NHPCO strongly believes that every terminally ill individual deserves the same level of hospice care, tailored to their individual needs, and is committed to providing it no matter where they live. As medical advances keep people alive longer, and as the baby boom generation ages,
more and more beneficiaries live out their final months or years as residents of nursing facilities. In 2009, 27.6% of Medicare decedents died in a nursing home.\textsuperscript{11}

In addition, as the Medicare hospice benefit has matured and beneficiaries have become more familiar with hospice care, the terminal diagnoses of those receiving hospice care has shifted from primarily cancer, as was the case in the early years of the benefit, and now more closely matches the demographics of the Medicare decedent population. Given these circumstances, it’s not surprising that hospices provide care to a significant number of nursing home residents; the Office of Inspector General (OIG), in a report issued in 2009, reported that 31% of Medicare Hospice beneficiaries resided in nursing homes in 2006.\textsuperscript{12} And in 2011, the OIG reported that hospice patients who are nursing home residents are more likely to be dying with non-cancer terminal conditions that have less predictable prognoses.\textsuperscript{13} On average, hospice patients residing in nursing facilities tend to be older, unmarried, and more likely to be dually eligible for Medicare and Medicaid than hospice patients living at home in their community. We believe terminally ill nursing home residents are among the frailest and most vulnerable patients we care for, and we feel strongly that these patients are particularly in need of the pain and symptom management expertise that hospices provide.

To the extent a site of service payment adjustment is intended to address concerns that some hospices may “target” nursing home patients because they are more likely to have longer lengths of stay that are more lucrative for the hospice, and that such hospices have a high percentage of their patients residing in nursing facilities, these concerns should be addressed in a targeted way that affects those hospices engaged in problematic practices, and not through reimbursement changes that adversely affect all hospice providers. If the concern is that such hospices may be admitting patients who aren’t eligible for hospice care, CMS’s response should address that issue. We do not believe such concerns are applicable to the vast majority of hospice programs. In fact, the median length of service for nursing home patients receiving hospice care between 2001-2008 was only 17 days and a quarter of all nursing home patients receiving hospice care during this time were enrolled in hospice for 5 days or less.\textsuperscript{14} CMS data shows that the median length of stay for all Medicare Hospice benefit patients has not demonstrably changed since 2000 – and remains at between 17 and 18 days.

We also would note that in response to MedPAC’s concerns in this area, Congress included a provision in the ACA requiring medical review of long stay patients when the hospice has a

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  \item Office of Inspector General, Medicare Hospice Care: Services Provided to Beneficiaries Residing in Nursing Facilities, OEI-02-06-00223, September 2009
  \item Office of Inspector General, Medicare Hospices that Focus on Nursing Facility Residents, OEI-02-10-00070, July 2011
\end{itemize}
specified percentage of such patients, but CMS has not implemented this requirement. As the hospice community has demonstrated in the past, it is willing to work with reasonable and responsible policy makers to clearly identify inappropriate behavior within the healthcare sector and work constructively to fashion workable solutions and then lead the hospice community in its implementation. Imposing a payment reduction that will affect ALL hospices and ALL Medicare hospice patients who reside in nursing facilities in order to address concerns about particular hospice programs with certain long stay patients in this setting would be an untargeted and ineffective solution.

We also would like to urge CMS, as well as other policymakers, to turn its attention to what we believe is a more significant problem, which is the persistently high number of extremely short-stay hospice patients. Approximately 35 percent of patients receive hospice care for 7 days or less, and about 50 percent of patients are in hospice for 17 days or less. While hospices are committed to helping all individuals at the end of life, no matter how short their stay in hospice, patients and families receiving hospice care for such a short period cannot enjoy the full value of the hospice benefit. Hospice was designed to be compassionate care, not crisis care, and hospices continually hear from their patients and family members that they wish they had come to hospice sooner.

It’s important to understand the facts and dispel some of the myths, half-truths and incomplete picture that have been portrayed about hospice care provided to nursing home residents. Providing care to patients residing in this setting is complex, both in terms of coordinating the services provided by the hospice and by the nursing facility, and because it is more likely to involve special challenges, such as patients who are typically older and more frail, who are more likely to have cognitive impairment, and whose family members involved in care decisions also are frail and elderly or who live far away. The need to coordinate care between the hospice and nursing facilities’ staff is time consuming, as is communicating and coordinating with family members making care decisions, who are more likely to be at a distance and less familiar with the patient’s condition and needs. We simply disagree with the allegation that hospice patients residing in nursing homes require less complex care and are less expensive to care for.

It’s also important to make clear that when a nursing home resident is determined to be terminally ill and elects to receive hospice care, the nursing home and the hospice delineate each entity’s roles and responsibilities through a written agreement. On Thursday, June 27, 2013, CMS published the final rule “Medicare and Medicaid Programs; Requirements for Long Term Care Facilities; Hospice Services (CMS-3140-F)” (“the LTCF final rule”). This sets forth the

15 2011, NHPCO National Data Set and/or NHPCO Member Database.
rules for nursing homes that enter into arrangements with hospices, and is the companion to the hospice condition of participation addressing such arrangements. The preamble states:

The requirements of this final rule simply clarify the roles and responsibilities of LTC facilities when they choose to contract with hospices to serve their residents. For more than a decade, States have regulated the overlapping relationship between LTC facilities and hospice providers... We believe it is in the best interest of the patients to regulate this overlapping relationship in order to improve the safety and quality of care provided to LTC residents who receive hospice services.\textsuperscript{16}

The long term care facility staff continues to be responsible for the care of residents, and is expected to play the role that a family caregiver would play if the patient were still residing in their own home in the community. The hospice is expected to provide the same level and type of services they would provide to that patient if they were in their own home, based on the specific needs and wishes of that patient and their family.

When a nursing home resident elects to receive hospice care, the nursing facility typically is precluded from providing a skilled level of care such as that provided in skilled nursing facilities under the Medicare Part A post-hospital extended care benefit. The nursing home, at this point, is providing a custodial level of care, and is paid for providing the patient’s “room and board”. It is made clear in both the hospice and the newly released long term care facility Conditions of Participation that the agreement between a hospice and nursing facility must set forth the services to be provided by each, and provide that it is the nursing facility’s responsibility to provide care “meeting the personal care and nursing needs that would have been provided by the primary caregiver at home at the same level of care provided before hospice care was elected.”\textsuperscript{17} The preamble to the LTCF final rule states:

Having a written agreement that clearly delineates roles, responsibilities, expectations, and communication strategies should enhance, rather than impede, the coordination of care. This rule, when paired with the hospice regulatory requirements for written agreements, required services, and designated hospice representatives, will provide the overall structure for LTC-hospice relationships and written agreements. The hospice and LTC facility must collaborate to develop a coordinated plan of care for each patient that guides both providers.\textsuperscript{18}

\textsuperscript{16} “Medicare and Medicaid Programs; Requirements for Long Term Care Facilities; Hospice Services; Final Rule,” 78 Federal Register 124 (27 June 2013) p. 38597

\textsuperscript{17} 42 C.F.R. §418.112(c)(4)

\textsuperscript{18} “Medicare and Medicaid Programs; Requirements for Long Term Care Facilities; Hospice Services; Final Rule,” 78 Federal Register 124 (27 June 2013) p. 38602
For patients dually eligible for Medicare and Medicaid, the room and board payment covered by Medicaid also doesn’t accommodate an increase in the custodial care services provided by the nursing facility staff as the patient’s condition declines. When patients are in their last weeks or months of life, their care needs typically increase and become more complex, and addressing those needs to adequately manage and palliate their pain and symptoms requires the special expertise and extra efforts of hospice.

CMS notes data indicating that hospice patients residing in nursing facilities receive more hospice aide visits than hospice patients at home, and suggests that the hospice aide may be replacing the facility aide rather than augmenting the care they provide. CMS also states its belief that a beneficiary who has a paid caregiver (e.g., a nursing facility aide) does not need as many services from a hospice aide because those services are being provided by the paid caregiver, and that hospice patients in nursing facilities should have much, if not most, of their need for aide services provided by the facility’s aide. We believe there is a misunderstanding of the care needs of dying nursing home residents, and a lack of appreciation for the special training and expertise involved in providing end of life care. And it assumes that the care provided by a nursing facility aide and a hospice aide is essentially the same.

We believe that the newly released LTCF facility final rule confirms the long term care facility’s responsibility for continuing services at the same level, whether or not hospice is involved, when the preamble to the rule states:

“facility’s services must be consistent with the plan of care developed in coordination with the hospice, and the facility must offer the same services to its residents who have elected the hospice benefit as it furnishes to its residents who have not elected the hospice benefit. Therefore, the hospice patient residing in a facility should not experience any lack of services or personal care because of his or her status as a hospice patient.”

Nursing facilities and their staff do a tremendous job providing care to their residents, whose needs typically have become too great for their families to manage in the home setting, but the reality is that each nursing home aide typically has to juggle many demands and provide care to multiple patients, so the assumption that they can provide the same attention to a hospice patient in a nursing home as would be provided to that patient by one or more loving family members at home, or that the needs of many of these patients may not be greater than those of patients being cared for at home, is simply unrealistic. As competent and caring as nursing home aides are, family members caring for their loved one are more able to be focused, attentive, engaged and present on a continuous basis. That is a simple and undeniable reality.

19 “Medicare and Medicaid Programs; Requirements for Long Term Care Facilities; Hospice Services; Final Rule,” 78 Federal Register 124 (27 June 2013) p. 38600
We urge CMS not to make assumptions or jump to conclusions about a finding that hospice patients in nursing homes receive more hospice aide services than those in the home setting, and use that to justify a payment adjustment that will affect all patients in that setting.

We also want to address the claim that it is less expensive for hospices to provide care to nursing home patients because of certain “efficiencies” that exist when hospices provide care to nursing home residents. While published data on hospice contracts found that 78% of US nursing homes had formal contracts with outside hospice programs in 2004, we believe the vast majority of them have no hospice patients or only a small number of hospice patients at any one time. So the implication that a majority of hospices often have a “wing” of patients in one nursing home and can save staff time and mileage by providing care to all of them in a fraction of the time it would take to do so in the community is just false.

The arrangement to coordinate care and services between the hospice and nursing facility is a complex one, and includes the requirement to communicate, collaborate and coordinate on an ongoing basis regarding any changes in the patient’s condition and changes in the plan of care, as well as orienting and training nursing facility staff in the hospice philosophy, including hospice policies and procedures. All of this requires additional time and effort by the hospice, not tracked in documentation of visits or visit intensity, rather than providing “efficiencies”. In addition, when nursing facility residents who are dually eligible for both Medicare and Medicaid elect to receive hospice care, Medicaid already reduces the amount it pays for room and board services by five percent, to account for potential overlap or efficiencies that may occur when the hospice also is providing care to those beneficiaries.

In summary, NHPCO strongly objects to any proposal to make a site of service adjustment that would reduce payments for hospice patients who reside in nursing facilities. We do not believe data support the allegations and assumptions that hospices generally enjoy “efficiencies” when they provide care to nursing home residents, or that the cares being provided overlaps or substitutes for care that is the responsibility of the nursing home. Equally important, is a full and comprehensive analysis that examines the "inefficiencies" of providing high quality end of life care in nursing facilities. Furthermore, the newly released LTCF final rule on the nursing home/hospice partnership speaks to the delineation of roles and responsibilities for each entity, and notes the importance of the written agreement in addressing possible overlaps in services. Any adjustment that shifts additional responsibilities onto the nursing home staff, as suggested by CMS, is putting more pressure on already overburdened nursing facility aides, and

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21 42 C.F.R. §418.112(d)-(f). 42 CFR §483.75(t)
threatens to diminish the care provided to some of the most vulnerable Medicare beneficiaries during their final days.

**Additional Data Collection**

NHPCO appreciated the opportunity to provide comments on the December, 2012 notice describing additional data collection and look forward to continued dialogue about the realistic collection of additional data, while reviewing the provider burden for such collection. In addition, the NHPCO Cost Report Work Group submitted detailed comments on changes to the hospice cost report and draft cost report forms more than four years ago, (June 2009) and will be submitting substantive comments on the PRA notice for the draft revisions to the cost report due June 28, 2013.

Thank you for the opportunity to comment. NHPCO looks forward to continuing dialogue about the issues raised in this proposed rule.

Sincerely,

J. Donald Schumacher, PsyD
President and CEO